

GLAUCOMA AWARENESS

Helen Baker

A thesis submitted to University College London for the degree
of:


DOCTOR OF PHILOSOPHY

Institute of Ophthalmology
University College London
September 2008

SIGNED DECLARATION

I Helen Baker, confirm that the work presented in this thesis is my own.

Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed:  .

ACKNOWLEDGEMENTS

Firstly and most importantly I would like to thank my supervisor Ian Murdoch. He saw in me a potential I never knew existed and without his faith in my abilities I would have never attempted such an enormous task. Through working together Ian has not only given me excellent academic council and been an enthusiastic, patient mentor he has become a great friend. It is a friendship I value greatly and I know will continue for many years to come.

I would also like to acknowledge the support of a number of other people who have made it possible for to complete this thesis. In particular I note:

All the patients, health professionals, public groups and actors who participated in my research.

Guide Dogs for the Blind communication team in particular Paul Day who stayed involved to the end. I would like to give special thanks to Robin Hutchinson who was instrumental at the start of this project. His laughter, enthusiasm and contacts have proved invaluable. Even though he no longer works for Guide Dogs for the Blind he has stayed committed to the project.

McCann Erickson who gave their resources for free. Particularly Stephanie Smith for her co-ordination and Kes Grey for his creative input. Without Kes I would have never even contemplated being able to use

television as a medium and would never have created such wonderful, colourful adverts.

Cowboy Films for producing the adverts free of charge.

BMRB and Ethnic Media Focus for their help with questionnaire design and administration.

Professor Roger Hitching and Sue Lydeard for their support and advice and Emma Cartwright for proof reading.

Judy Green for introducing me to qualitative research.

Daksha Patel, Kamal Sharma, Minakshi Handa and Poornima Rai for speaking a variety of Asian languages when required and translating from Hindi to English and English to Hindi.

Julia Theodossiades, Uma Patel and Aneel Suri for allowing me to use and interpret their data on glaucoma referrals and PPV rates in Ealing.

Last but by no means least I would like to thank my parents for their support and interest and my husband Chris for his love, unwavering faith in my academic capabilities and for generally being great.

ABSTRACT

This thesis investigates three different aspects of glaucoma awareness using both quantitative and qualitative methods.

Patient Awareness:

This qualitative study looked at patients perceptions of glaucoma.

Participants (N=28) reported low levels of awareness of glaucoma prior to their diagnosis and assumed that symptoms were the 'normal' deterioration of eyesight. As symptoms have a gradual onset, participants had learnt to cope with diminishing sight ability. Findings suggested health promotion a priority to increase public awareness of the existence and symptoms of glaucoma among those at high risk.

Current public awareness:

This study looked to document public awareness and knowledge of glaucoma.

The study used health knowledge questionnaires in three different populations:

1. nationally representative sample of 1009 people
2. telephone Interviews – 500 Isle of Wight, 226 Ealing
3. face-to-face interviews – 300 Ealing

Between 71-93% of those interviewed by telephone had heard of glaucoma. However, only 23% of those interviewed face-to-face in Ealing reported having heard of glaucoma. We found a relatively high level of

awareness and knowledge of glaucoma in the general UK population but identified at least one pocket of poor knowledge in a specific sub-population.

Can we change awareness?

This study investigated whether a public health campaign could increase awareness and change help-seeking behaviour with respect to ocular health with residents in Southall, Ealing aged 60+. The health knowledge questionnaire from the previous study was used to assess the campaign.

The health campaign comprised of four components.

1. Television
2. Local Press
3. Local Radio
4. Places of worship

The results showed a significant increase in the number of people who had heard of Glaucoma rising from 22% to 53%. Before the intervention most people had heard about glaucoma from their GP, friend or relative. After intervention the majority (69%) had heard of glaucoma from the radio.

This study showed a significant increase in awareness from using different kinds of media and showed radio to be the most effective in the

target community. Although the campaign raised awareness it did not show a change in help seeking behaviour.

CONTENTS

Title

Acknowledgements

Abstract

Contents

List of Tables

List of Figures

1.0 Health

1.1 Introduction

1.2 Definition

1.3 Health

1.4 Models of Health Promotion and Education

1.4.1 Ideological Basis for Models of Health

1.4.1.1 Educational Model

1.4.1.2 Preventive Model

1.4.1.3 Empowerment Model

1.4.2 Technical Basis for Models of Health

1.4.2.1 Health Belief Model (HBM)

1.4.2.2 The Theory of Reasoned Action

1.4.2.3 The Health Action Model (HAM)

1.4.2.4 HAM and the Belief System

1.4.2.5 HAM and the Motivation System

1.5 Health Education and Awareness

1.5.1 Health Promotion in Schools

1.5.2 Health Promotion in Hospitals

1.6 Mass Media and Health Promotion

1.6.1 Media Advocacy

1.6.2 Examples of Health Campaigns Using Mass Media

1.6.2.1 Smoking

2.0 Visual Impairment

2.1 Introduction

2.2 Definition of Visual Impairment

2.3 Visual Impairment Worldwide

2.3.1 Number of Visually Impaired Worldwide

2.3.2 Causes of Visual Impairment Worldwide

2.4 Visual Impairment in the UK

2.4.1 Number of Visually Impaired in UK

2.4.2 Causes of Visual Impairment in the UK

3.0 Glaucoma

3.1 Classification of Glaucoma

3.1.1 Definition of Glaucoma

3.1.2 Different Types of Glaucoma

3.2 Glaucoma Prevalence

3.2.1 Primary Glaucomas

3.3 Primary Open-Angle Glaucoma (POAG)

3.3.1 Nature of Disease

3.3.2 Glaucoma Case Finding

3.4 Cost of Glaucoma

3.5 Glaucoma Knowledge

4.0 Research Methods

4.1 Introduction

4.2 The Difference Between Qualitative and Quantitative Research

4.3 Qualitative Research Methods

4.3.1 Sampling Strategies

4.3.2 In-Depth Interviews

4.3.3 Focus Groups

4.4 Quantitative Research Methods

4.4.1 Questionnaires

4.4.2 Good Questions

4.4.3 Pre-testing

4.4.4 Mail and Self-Administered Questionnaires

4.4.5 Telephone Interviews

4.4.6 Face-to-Face Interviews

5.0 Patient Awareness

5.1 Introduction

5.2 Methods

5.2.1 Sampling Strategy

5.2.2 Interviewing Techniques

5.2.3 Analysis

5.3 Key Findings

5.3.1 Triggers

5.3.2 Unexpected Diagnosis

5.3.3 Treatment

5.3.4 Driving

5.3.5	Reading
5.3.6	Cost of Coping
5.3.7	Perceptions of Blindness
5.4	Discussion
5.5	Conclusion
6.0	Pilot Study
6.1	Introduction
6.2	Study Location
6.3	Methods
6.3.1	Advert in Local Paper
6.3.2	Interview on Local Radio
6.3.3	Questionnaire
6.4	Results of Advert Piloting
6.5	Results of the Study
6.5.1	Southall
6.5.2	Isle of Wight
6.6	Discussion
6.7	Conclusion
7.0	Public Awareness
7.1	Introduction
7.2	Methods
7.2.1	Questionnaire
7.2.2	Ethical Approval
7.3	Results
7.4	Discussion

7.4.1 Principal Findings

7.4.2 Implications for Health Professionals and Policy Makers

7.4.3 Limitations

7.4.4 Relationship to Other Studies

7.5 Conclusion

8.0 Public Health Campaign

8.1 Introduction

8.2 Methods

8.2.1 Study Location

8.2.2 Baseline and Outcome Measures

8.2.3 Advertising Campaign

8.2.3.1 Role of Advertising Agency McCann Erickson

8.2.4 Optometric Data

8.2.5 Positive Predictive Power of Referrals to Ealing Hospital

8.3 Advertising Campaign

8.3.1 Introduction

8.3.2 Press

8.3.3 Radio

8.3.4 Television

8.3.5 Places of Worship

8.4 Results and Analysis of Advertising Campaign

8.4.1 National Sample

8.4.2 Demographics

8.5 Results

8.5.1 Validity

8.5.2 Specific Responders

8.5.3 Logistic Regression

8.6 Results and Analysis of Optometric Data

8.6.1 Analysis of Optometrist Appointment and Referral Data

8.6.2 Why People go for Eye Tests

8.7 Results of Positive Predictive Value

8.8 Discussion

8.8.1 Principal findings

8.8.2 Relationship to Other Studies

8.8.3 Strengths and Limitations

8.8.4 Implications for Health Professionals and Policy Makers

8.9 Conclusion

9.0 Unifying Summary

9.1 Introduction

9.1.1 Summary of Research

9.2 Summary of Background Literature

9.2.1 Health

9.2.2 Visual Impairment

9.2.3 Glaucoma

9.3 Patient Awareness

9.4 Public Awareness

9.5 Media Campaign

10.0 Future Recommendations

Abbreviations

Bibliography

Research Support and Commercial Interests

Appendices

A. Glaucoma Knowledge Questionnaire

B. Peer reviewed publications originating directly from this thesis

LIST OF TABLES

NUMBER	TITLE
2.1	Estimates of numbers of people visually impaired over the age of 64
3.1	Rudnicka et al's estimated prevalence according to age and race
3.2	Annual Glaucoma Costs – UK (2002)
3.3	Papers on knowledge of glaucoma
4.1	The key differences between qualitative and quantitative research
4.2	Sampling Strategies
4.3	In-depth interview questions pathway
4.4	Framework Technique
4.5	Features of different types of survey
5.1	Study Participants
5.2	Key Prompts
6.1	Southall Demographics
6.2	Isle of Wight Demographics
7.1	Distribution by Sex, Age, Area and NSECa for Having Heard of Glaucoma
7.2	Numbers who had Heard of Glaucoma
7.3	Odds Ratios for the Associations Between the Outcome “Having Heard of Glaucoma” and Sex, Age, Sampling Source and NSECa
7.4	Level of Knowledge about Glaucoma

- 8.1 Summary of Media Output
- 8.2 Baseline Data Including National Sample on Number who had Heard of Glaucoma
- 8.3 Sex
- 8.4 Religion
- 8.5 Number who had Heard of Eye Disease Pre and Post Intervention
- 8.6 Number who had Heard of Glaucoma but not other diseases
- 8.7 Where Did You Hear of Glaucoma?
- 8.8 Have you Heard or Seen an Advert for Glaucoma?
- 8.9 What Radio Stations Do You Listen to?
- 8.10 Percentage of Those Who Listen to Radio station who had Heard of Glaucoma
- 8.11 Number who have worked in the Health Field
- 8.12 Numbers who wear glasses/contact lenses
- 8.13 How much do you know about the disease?
- 8.14 Detailed questions about glaucoma
- 8.15 Number who had heard of glaucoma split by age
- 8.16 Number who had heard of glaucoma split by sex
- 8.17 Number who had heard of glaucoma split by religion
- 8.18 Number of reported tests in the last 12 months
- 8.19 Proportion who had heard of glaucoma who did not have health checks

- 8.20 Number of people who had heard of glaucoma who had
 been for an eye test
- 8.21 Proportion who had heard of glaucoma and reported recent
 eye test pre and post intervention
- 8.22 Crude odds of numerous variables for the outcome of
 having heard of glaucoma
- 8.23 Average appointments per week for twelve practices with
 data collected in 2004 and 2007
- 8.24 Estimated number of sight tests over 26 week collection
 periods in 2004 and 2007 for all optometric practices in
 Borough of Ealing
- 8.25 Estimated number of cases referred to hospital for
 suspected glaucoma over 26 week collection periods in
 2004 and 2007 for all optometric practices in the Borough of
 Ealing
- 8.26 Reasons why people go for eye tests
- 8.27 Positive predictive values pre and post intervention

LIST OF FIGURES

NUMBER	TITLE
1.1	Dimensions of Health
1.2	Health Belief Model: major components and linkages
1.3	The Theory of Reasoned Action: major components and linkages
2.1	Global estimate of visual impairment by WHO region
2.2	Global causes of blindness as a proportion of total blindness in 2002
2.3	Estimated causes of visual impairment in the UK
3.1	Glaucoma classification
3.2	Cumulative proportion of open-angle (OAG) incidence in white and black persons in a simulated United States population in which derived incidence values are applied to a cohort of persons ranging in age from 30 to 100 years of age
4.1	Steps in the process of survey research
5.1	In-depth interview in Leeds – Taking consent
6.1	Baseline and Outcome Questionnaire
6.2	Advert used in Southall local paper
6.3	Advert used in Isle of Wight paper
6.4	Advert used on Southall Radio
6.5	Advert used on Isle of Wight Radio
6.6	Southall percentage data pre and post
6.7	Isle of Wight percentage data pre and post

7.1	Isle of Wight
7.2	Southall Ealing
8.1	Advert in English
8.2	Advert in Hindi
8.3	Radio Advert
8.4	Advert 1 "In a Bit"
8.5	Advert 2 Curtains
8.6	Advert 3 Hellooo!
8.7	Poster for places of worship
8.8	Percentage distribution of age group interviewed by pre/post intervention
8.9	The proportion who had heard of different diseases pre/post intervention
9.1	Summary of Research

1.0 HEALTH

1.1 Introduction

This chapter will look at different models of health promotion and education, including health awareness and some of the previous work carried out in this field.

1.2 Definition

Health – “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [1]

1.3 Health

Health is a broad concept which can embody a huge range of meanings from the narrowly technical to the all-embracing moral or philosophical. Holistic health means taking into account the different elements, their influences and interactions. *Figure 1.1* looks at the dimensions of health. The inner circle represents individual dimensions of health. Physical health concerns the body, whereas mental health concerns the ability to make judgments. Emotional health refers to the recognition and appropriate discharge of feelings. Social health relates to the integration

of somebody in a web of relationships. Spiritual health is the recognition and ability to put into practice moral or religious principles or beliefs. Sexual health is the acceptance and ability to achieve a satisfactory expression of ones sexuality.

The two outer circles are broader dimensions of health which affect an individual. Societal health refers to the link between health and the way a society is structured. This includes the basic infrastructure necessary for health: shelter, peace, food, income, access to services and the degree of integration or division within society. Environmental health refers to the physical environment in which people live, and includes housing, transport, sanitation and pollution.

All these factors influence health choices and perceptions of health. This thesis is directly concerned with health promotion and education.

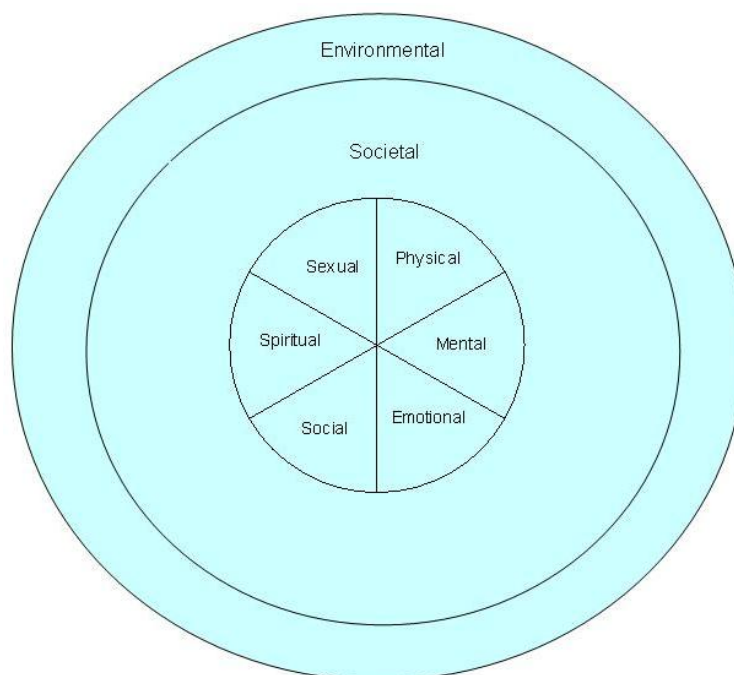


Figure 1.1: Dimensions of Health. Adapted from Ewels & Simnett. [2]

1.4 Models of Health Promotion and Education

Health promotion or health education models are of two types: ideological (value based) and technical (theory based). The ideological seeks to provide a simplified but reasonably accurate explanation of how sets of values can give rise to different constructions of the major strategic purpose of health and illness related action. Technical models come in the form of theories and provide insights into human health and illness related behaviour. This aims to help practitioners translate ideological commitments into actions.

1.4.1 Ideological Basis for Models of Health

1.4.1.1 Educational Model

Education can be seen as both communication and teaching. Education as communication has only ever been seen as an ideological dimension, centring on the beliefs that people have a right to knowledge and that knowledge is power. The education approach does not set out to persuade or motivate change in a particular direction. Education is intended to have an outcome but it should be based on voluntary choice and it may not be the preferred choice.

The educational model is based on a set of assumptions about the relationship between knowledge and behaviour: that by increasing

knowledge there will be a change in attitudes which may lead to a change in behaviour. It is doubtful that information alone will change behaviour. Even the desire and ability to change is no guarantee that the individual will do so. A purely educational approach has two significant barriers to rational decision making. The first centres on individual limitations, while the second is the potentially unhealthy influence of environmental factors. Freedom of choice can be constrained by many factors, such as the presence of addictions or compulsive behaviours. The effect of negative socio-economic and material circumstances can also play a big part in limiting an individual's choice.

1.4.1.2 Preventive Model

This model comes from the medical model where the body is viewed as a machine and the prime function of medicine is to keep it in running order and to repair the machine when it malfunctions. The preventive model of health education is concerned with contributing to the goals of preventive medicine and aimed at reducing morbidity and premature mortality. Activity is targeted towards whole populations or high-risk groups to increase medical interventions which will prevent ill health and premature death, such as immunization and screening.

The rationale for this model is:

1. Curative medicine has a limited capability for managing the major (Western) burden of chronic degenerative disease and key infections such as AIDS. Moreover, its practice is characterised by accelerating costs and side effects caused by treatments.
2. Prevention is therefore better (and often cheaper) than a cure.
3. Since human behaviour plays a significant part in the aetiology of many diseases and in the management of all of them, education is needed to persuade people to act appropriately.

This model is based ultimately on reduction of disease rates and associated mortality. This approach relies on infrastructure capable of delivering a screening or an immunization programme, including trained personnel, equipment and facilities. Even if all this is available it will only be effective if people can be persuaded to use them. It is a long-term process and a more popular measure capable of short-term evaluation is the increase in the percentage of the target population being screened or immunized.

1.4.1.3 Empowerment Model

This approach aims at people identifying their own concerns and having the skills and confidence to act upon them. Its central concern is with the empowerment of communities and individuals. It incorporates elements of both the education and the preventive models. However, whereas the preventive model seeks to persuade and coerce, the education model

merely aims to provide education. The empowerment model seeks to enable choice by building an individual's capacity to make decisions and to remove the broader environmental barriers militating against genuine freedom to choose.

Its main principles are:

1. It makes a direct contribution to an individual's health by influencing health and illness-related behaviours. It does not seek to persuade, coerce and cajole, but rather contributes to self-empowerment. If successful it enhances individual's control over their lives and their health.
2. It follows the preventive model in its concern to influence health services but its function is different. It contributes to 're-framing' perceptions of what health services should be.
3. It seeks to mobilise community opinion and concentrate public pressure on government and other powerful agencies that are policy creators. It does this by critical consciousness raising and community empowerment.

1.4.2 Technical Basis for Models of Health

Tones states that 'A sound theoretical framework can provide a substantial basis for practice' [3]. The main requirement for such a framework is that it should explain how people make health-related

decisions, whether individually or *en masse*. The majority of health promotion theories come from behavioural and social sciences. They borrow from various disciplines such as psychology, sociology, management, consumer behaviour and marketing. Such diversity reflects the fact that health promotion practice is not only concerned with the behaviour of individuals but also with the ways in which society is organised and the policies and organisational structures that underpin social organisation. The main theories are discussed below; they are not mutually exclusive but represent the main aspects of behaviour that have been modelled.

1.4.2.1 Health Belief Model (HBM)

HBM is one of the longest established theoretical models designed to explain health behaviour by better understanding beliefs about health. It was originally developed to explain why people failed to utilise health services [4] and has undergone many revisions [5]. The central theme of the HBM is that individuals will not adopt health behaviours designed to prevent specific diseases unless they believe they are susceptible to the disease or disorder in question and that the recommended actions will be effective (see *Figure 1.2*).

The HBM asserts that an individual must believe:

1. they are susceptible to a given disease

2. the disease or disorder is serious
3. the proposed preventive action will be beneficial: i.e. will effectively protect the individual from the threatening disease
4. these benefits will outweigh any costs or disadvantages that might be incurred as a result of the preventive action.

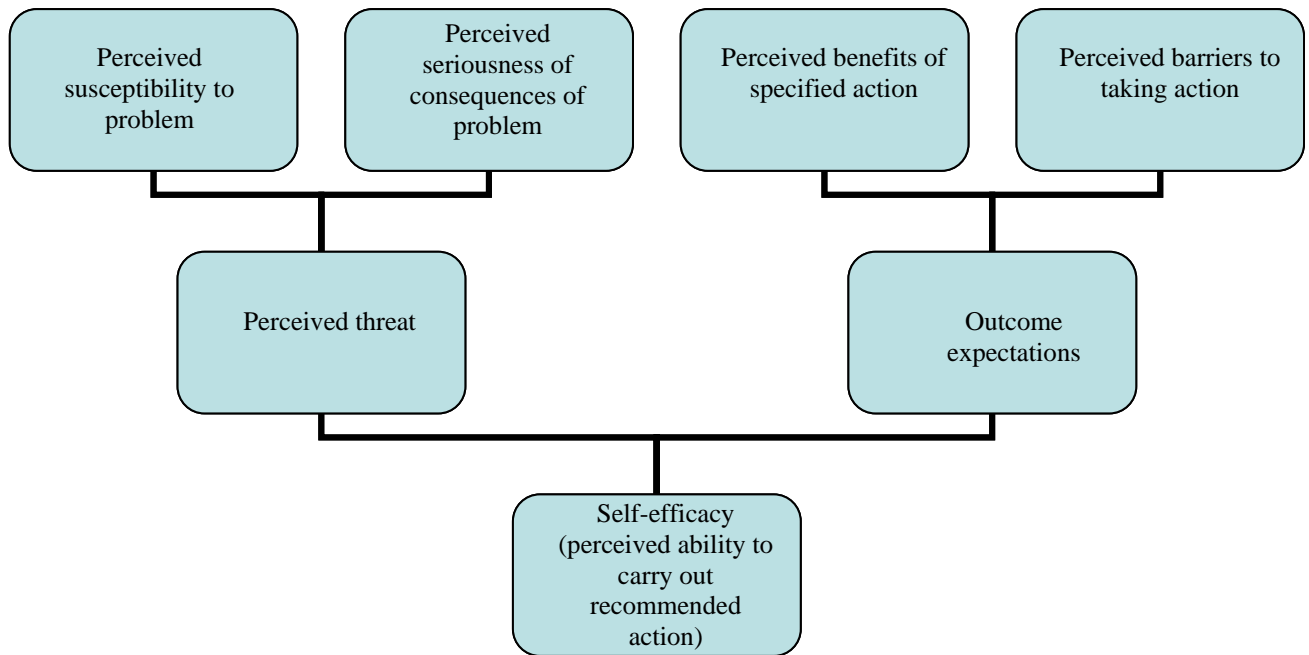


Figure 1.2: Health Belief Model: major components and linkages

In addition, the likelihood of action will be enhanced if the individual has a positive general attitude to health and if some incentive or trigger is provided.

The most important indicators of success which are highlighted by the HBM are:

1. the four key beliefs (how many of these does the individual hold and how strongly?).

2. the number of preventive actions undertaken
3. the successful delivery of appropriate 'clues to action'.

The HBM is weak both in relation to precise examination of social influences and also to emotional aspects of human behaviour.

1.4.2.2 The Theory of Reasoned Action

Fishbein and Ajzen wrote the theory of reasoned action model aim to complement and improve the HBM analysis of health decision making [6]. It does this by separating belief from attitude and emphasizing the paramount importance of the influence of 'significant others' on an individual's 'intention to act'. The gap between intention and practice and the relationship between beliefs, attitudes, normative factors, intention and practice are shown in *Figure1.3*.

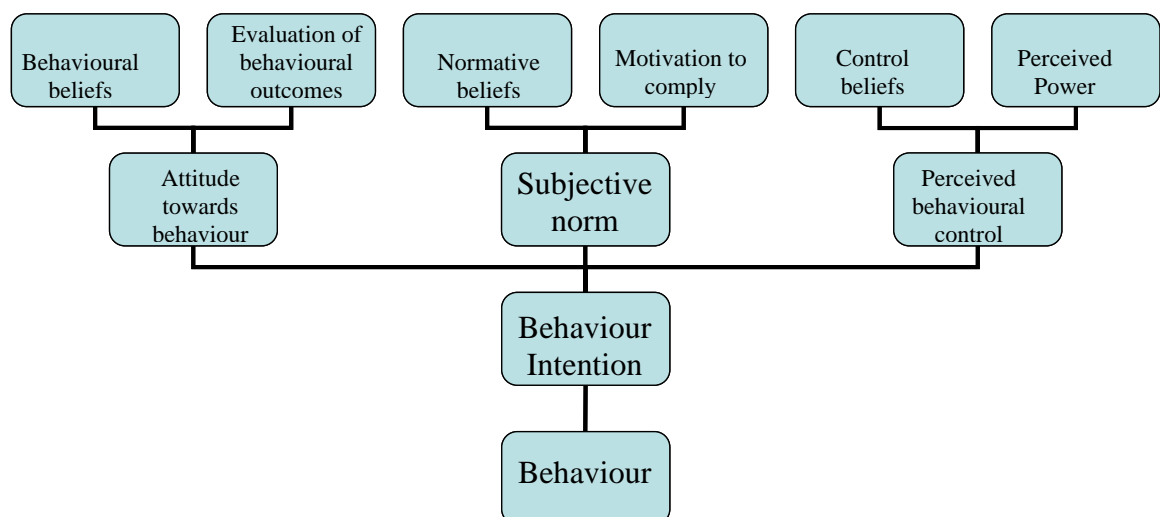


Figure 1.3. The Theory of Reasoned Action: major components and linkages

The Fishbein model would typically generate the following indicators:

1. an often long list of different beliefs about given specific health action
2. the attitude which is created by these beliefs
3. a series of beliefs about the likely reaction of various significant others to the proposed behaviour
4. the individual's degree of motivation to comply with the perceived wishes of the significant others
5. the strength of the resulting behavioural intention
6. the actual behavioural outcome itself

The theory for reasoned action provides valuable insight into key factors that influence behaviour, and provides a strong indication of the importance of perceived social norms and the understanding of short-term consequences in shaping health behaviour.

1.4.2.3 The Health Action Model (HAM)

This is a Mapping model which seeks to provide a comprehensive framework within which the major variables influencing health choices and actions, and their relationships are described and categorised. This model is capable of incorporating the first two models. Other health-related models such as Baric's Social Intervention Model [7], Friedson's Lay Referral System [8], and the important work on health locus of control by Rotter [9] are also consistent with HAM.

Routines, quasi-routines and discrete single time choices are the three categories of health action:

1. Routines – behaviours that have become habitual, often from previous socialisation. Routine practices of any kind are not under direct conscious control and do not require conscious decision. One of the main goals of health education is to ensure that many health practices become automatic.
2. Quasi Routines - normative pressure maybe so great that it precludes choice. One different action may be so reprehensible that only reckless deviants would ever contemplate such a course of action. In this case the 'normal' alternative would be described as a quasi-routine.
3. Discrete Single Time Choices - attempts to define the factors leading to an individual deciding to perform a specific act. These could either be changing a long-term habit or adopting a totally new practice. It is influenced by the belief system, the motivation system and the normative system.

Experience can influence or alter all decision making.

1.4.2.4 HAM and the Belief System

Fishbein and Ajzen examine belief further. [10]. Two notions about beliefs are: firstly, beliefs may be salient (active) or latent (existing but not active). Salient beliefs are conscious and arguably more likely to influence health actions. Latent beliefs may well make a significant impact if made salient by, for example, a process of 'values clarification'.

Secondly, belief strength will vary and is quantifiable. Clearly a high level of conviction will be more likely to contribute to a decision than a state of doubt and uncertainty. Indicators of belief should not only provide a measure of how important they are but should also indicate the strength with which they are held and whether they are active or inactive.

Self-belief is the most important category. The sum total of such beliefs is known as self-concept. This includes the HBM variable of perceived susceptibility. Perception of susceptibility should, other things being equal, facilitate action. Individuals who see themselves as being in charge of their lives and have the capacity to act logically and decisively are known as 'copers'. The likelihood of these people adopting a given health action which they believe to be sensible is much greater than for those with a different self concept. People who believe in fate or that life is governed by a higher being are less likely to be motivated to change.

1.4.2.5 HAM and the Motivation System

The motivation system is the elements which determine an individual's attitude to an action and their intention of adopting it.

Part of this is down to the individual's value system. Values are acquired through socialisation; they are effectively charged sets of beliefs referring to particular aspects of experience. Attitudes are more specific than values. They describe feelings towards particular issues.

Fishbein & Ajzen show how attitude relates to belief.

...and attitude (refers) solely to a person's location on a bipolar evaluative or affective dimension with respect to some object, action, or event. An attitude represents a person's general feeling of favourableness towards some stimulus object.....[10]

Each value will produce a large number of attitudes. The acquisition of new beliefs will, in turn, generate new attitudes generated by the value systems. It is much more difficult to change an attitude which derives its motivational force from several values, especially where such values are deep-seated and important. The most powerful and influential value is self-esteem. This relates to self empowerment discussed in Section 1.4.1.3.

The motivation system also includes 'drives'. The HAM recognises that certain basic and powerful influences may override socially acquired values and attitudes. Hunger, sex and pain are all drives. It is also used to refer to those acquired motivators having drive-like qualities such as drug addiction.

Sometimes there may be no obvious drive but the presence of certain emotional states may signify the existence of motivational factors derived from drives. For instance, guilt and anxiety may usefully be considered a diluted down version of pain or fear.

The motivation system is a composite of different drives, values and attitudes having different emotional charges and giving rise to a particular level of arousal – or 'push' to take action.

1.5 Health Education and Awareness

Awareness – Having knowledge or realisation.

"Knowing that something exists, or having knowledge or experience of a particular thing" (from Cambridge Advanced Learner's Dictionary)

Many healthcare providers are seeing health education and health awareness as a way of contributing to the promotion of community and individual health. Tones and Tilford say:

“Health Education is any intentional activity that is designed to achieve health or illness related learning, i.e. some relatively permanent change in an individual’s capability or disposition. Effective health education may, thus, produce changes in knowledge and understanding or ways of thinking; it may influence or clarify values; it may bring about some shift in belief or attitude; it may facilitate the acquisition of skills; it may even effect changes in behaviour or lifestyle” [3]

There is debate and disagreement when we ask what is the purpose of health education? Tones discusses that its aim should not primarily be to change behaviour but to create understanding. It should provide skills to help the learner make ‘rational’ decisions and to help people clarify their values to assist in voluntary decision making. In this context, using persuasion to coerce individuals into adopting ‘medically approved’ behaviours is not true education [11]. In real settings these methods are frequently used and come under the banner of health education and health promotion. Freire was the influence on critical conscious raising [12]. The driving force of the Freirean principle is *praxis* – the translation of reflection into action.

Public Health Advocacy has been viewed as one of the most significant components of health promotion since it first achieved wider acclaim in the Ottawa Charter [13]. Chapman and Lupton discuss its principles and ideology and create a formulation [14]. Central to this formulation is the use of media advocacy, i.e. the use of mass media as a means of critical consciousness raising in pursuit of social and political change.

The fact that health education can be successful in achieving its radical goals is illustrated by the banning of tobacco advertising in Australia. In 1992 the tobacco industry lost its freedom to promote its products. This was a victory for the Australian anti-smoking movement who not only stopped a trans-national industry's ability to promote its products freely, but also saw a one third fall in adult *per capita* cigarette consumption [15]. The fact that, against all odds, relatively powerless public health groups with few resources were able to win battle after battle against the economic and political clout of the tobacco industry makes this achievement sit comfortably in the history of modern public health as one of the all time great victories.

The power of public health advocacy can be seen in other international known examples such as: campaigns to oppose the oil and automobile industries' resistance to removing lead from petrol; [16] the international movement against the Nestlé company's continuing promotion of breast milk substitutes, particularly in less developed countries; [17] and ACT UP (AIDS Coalition to Unleash Power) whose major achievement in the

AIDS control field has been “to energize the fight against AIDS with an urgency that has translated into drug approvals, lower prices for medications, and increased funding for AIDS research and care.”[18]

Health education can take place in many settings and many forms. It may be a particular location, agency or organisation, such as family or work place or the more informal community. Schools and hospitals are settings which are often used to provide health education and are more likely to use other forms such as individual education rather than mass media.

1.5.1 Health Promotion in Schools

Schools have been identified as one of the main settings for health promotion. They have the potential to:

- reach a significant proportion of those of school age
- reach people at a particularly significant stage of life in the development of health knowledge, attitudes and behaviours and the capacity , therefore to influence current and future health
- build links with communities and develop two-way actions that can influence health
- reach children with preventive health services

Efforts to secure the provision of both health education in schools and specialist school health services have a relatively long history. The stimuli

for the development of health education and related activities in schools have varied over time and between countries but it is acknowledged that the World Health Organisation (WHO) has made a particular contribution to setting the agenda for thinking and practice.

1.5.2 Health Promotion in Hospitals

Health care institutions are often seen as the ideal setting to contribute to the promotion of community and individual health. Hospitals have been identified as a key setting for health promotion. Hospitals exist to provide treatment and care but they also offer unique opportunities for more general health promotion for patients, staff and all who have dealings with them. Prior to a focus on general health, hospitals have seen a slow development of specific health promotion policies such as in the fields of nutrition, smoking and breastfeeding.

1.6 Mass Media and Health Promotion

The two key features of mass media are their mass audience and the fact that there is no inter-personal communication between the originator and recipient of the message. A successful community programme incorporates mass media as an element within a whole programme. Over the years, effectiveness and efficiency have been debated. However, rather than asking whether mass media work, it is more important to look at what kind of effect might be expected from various kinds of media used

in wide-ranging situations and contexts to present different sorts of message about diverse subjects to distinct target groups.

Early theory of mass media has been described as the 'hypodermic model'[19]. Mass media are considered to exert a direct effect on the mass population at which they are targeted. The media message is 'injected' into a passive community: if it is not effective, either a higher level of audience exposure or a more powerfully persuasive message is needed. This model was given power by Dr Goebbels and wartime propaganda and was reinforced by case studies in which mass media did in fact have a direct impact on the population. Cantril's [20] analysis of the dramatic impact of Orson Welles' fictional broadcast [21] of H.G.Wells' *War of the Worlds* [22] provides one of the best examples of the direct effects of media. Thousands of American listeners assumed the story of an imminent alien invasion from outer space was real, and panic spread as people tried to flee. Mendelsohn [23] challenged the 'direct effect' model of mass media and replaced the image of a hypodermic with that of an aerosol. He states:

“We now begin to look at mass communication as sort of an aerosol spray. As you spray it on the surface, some of it hits the target; most of it drifts away; and very little penetrates.”

The media influence process is a complex one and, in normal circumstances, mass media will not easily change peoples' behaviour unless individual motivation and normative influences are favourable.

1.6.1 Media Advocacy

Mass media can be limited in its capacity to influence individual health choices due to major political barriers. Mass media using 'media advocacy' can be extremely effective in consciousness-raising. Wallack notes:

“media advocacy promotes a range of strategies to stimulate broad-based media coverage in order to reframe public debate to public health problems. It does not attempt to change individual risk behaviour directly but focuses attention on changing the way in which the problem is understood as a public health issue.” [24]

Media advocacy can sometimes be mistaken for social marketing but Tones [25] debates it is more than social marketing as it incorporates social consciousness-raising. It can be used to influence policy makers and encourage social change. Media advocacy in public health plays a role in educating the public, swaying public opinion or influencing policy makers. Mass media and media advocacy need to work together to provide comprehensive and effective public health campaigns.

Naidoo and Wills [26] state it is now widely accepted that mass media including media advocacy can:

- raise consciousness about health issues

- help place health on the public agenda
- convey simple information
- change behaviour if other enabling factors are present

Factors which enable behaviour change include existing motivation and supportive circumstances.

Using media is more effective if:

- it is part of an integrated campaign including other elements such as one-to-one advice
- the information is new and presented in an emotional context
- the information is seen as being relevant for “people like me”

Mass media cannot:

- convey complex information
- teach skills
- shift people’s attitudes or beliefs. If messages are presented which challenge basic beliefs, it is more likely that the message will be ignored, dismissed, or interpreted to mean something else
- change behaviour in the absence of other enabling factors

1.6.2 Examples of Health Campaigns Using Mass Media.

Obesity, coronary heart disease and smoking are the three areas that have received the most publicity and government funding in the western

world. Mass media is often linked with Local Health Authority programmes and very few are evaluated for effectiveness. This is especially the case with the mass media side where, if they are any, they are published in-house with very few reaching peer-reviewed journals. Cochrane has done reviews of interventions for prevention of coronary heart disease [27] and childhood obesity interventions [28] but neither really look into the mass media aspect. The subject with most published data is smoking which I will now consider in further detail.

1.6.2.1 Smoking

After the White Paper 'Smoking Kills' in 1998, [29] the UK government put substantial resources into an anti-smoking publicity campaign and smoking cessation treatment services within the NHS. At the time there had been very few studies into the effect of anti-smoking publicity campaigns and the last published UK study assessing anti-smoking television advertisements was back in 1987 [30]. The Health Education Authority's anti-smoking television advertising campaign in England in 1992 looked to address this and was evaluated by McVey and Stapleton [31]. Their aim was to evaluate the effectiveness of anti-smoking television advertisements both in motivating smokers to give up and in preventing relapse in those who had already given up. Three levels of intervention were monitored: No intervention, televised advertisements and a combination of television with local tobacco control network support. The television advertisements were screened in two phases over

18 months. Self reports of cigarette smoking were assessed and compared between the three levels of intervention before and after the campaign. After 18 months 9.8% of re-interviewed smokers had stopped and 4.3% had relapsed. There was no evidence of an extra effect of the local tobacco control network when combined with media and its effect was not assessed individually. There was also no evidence of any intervention effects after the first phase of the television media campaign, including no effect of varying intensity of the advertisements. McVey and Stapleton conclude that the anti-smoking television campaign was effective in reducing smoking prevalence through encouraging people to stop and helping to prevent relapse in those who had already stopped. They state that the lack of an effect after the first phase of the campaign indicates that advertising at this intensity requires a prolonged campaign. The authors also acknowledge that the effects of the campaign have to be measured in relation to concurrent anti-smoking activity: For example, the “No Smoking Day” campaign and advertisements for nicotine replacement therapy that were running at the same time.

The effects of 22 years of the “No Smoking Day” have been looked at by Owen and Youdan [32] This is a low budget campaign that seeks to attract publicity by creating news stories and events to attract media coverage. It does not have the budget to pay for advertisements. Initially the campaign encouraged people just to quit for the day but by the mid 1990’s the emphasis shifted to encouraging smokers to quit for good. Owen and Youdan found that awareness of “No Smoking Day” was lower

in 2004 than in 1986 but was still high at 70% for all smokers.

Participation has fluctuated over the years ranging from 7% - 19%.

Participation was 14% in 2004 and was the equivalent to 1 in 7 of UK smokers claiming to quit or reduce their consumption on the day. Among those who participated, 11% were still not smoking three months after the day. They conclude that "No Smoking Day" is successful in reaching smokers. With only a small budget, this public awareness campaign, supported by local activities, appears to be effective in helping smokers stop.

Bala et al have done a Cochrane review of mass media interventions for smoking cessation in adults [33] but it does not contain any interventions in the UK. They looked at eleven campaigns of variable scale and quality. Five large studies out of nine which reported smoking prevalence found some positive changes in smoking behaviour. Three large studies out seven that measured quantity of tobacco smoked found reductions. Over half of the studies which measured quit- rates reported significant increases in abstinence, but this finding was difficult to interpret because studies used different definitions of smoking, smokers and quit attempts. They conclude that there is evidence that comprehensive tobacco control programmes which include mass media can be effective in changing smoking behaviour in adults, but the evidence comes from a variable group of studies. The intensity and duration of mass media campaigns may influence effectiveness, but length of follow-up and concurrent events in the community make it difficult to verify.

2.0 VISUAL IMPAIRMENT

2.1 Introduction

This chapter will look at visual impairment worldwide and in the UK. It will give the most recent estimates for numbers visually impaired and will look at the causes of visual impairment.

2.2 Definition of Visual Impairment

The 10th Revision of the of the WHO International Statistical Classification of Diseases, Injuries and Causes of Death, defines low vision as “visual acuity of less than 6/18, but equal to or better than 3/60, or corresponding visual field loss to less than 20 degrees, in the better eye with best possible correction”. Blindness is defined as “visual acuity of less than 3/60, or corresponding visual field loss to less than 10 degrees, in the better eye with best possible correction”. Visual impairment includes low vision as well as blindness [34].

2.3 Visual Impairment Worldwide

2.3.1 Number of Visually Impaired Worldwide

WHO estimates that globally, in 2002, more than 161 million people were visually impaired, of whom 124 million people had low vision and 37 million were blind [35]. However, refractive error as a cause of visual impairment was not included, which implies that the actual global magnitude of visual impairment is greater. Worldwide for each blind person, an average of 3.4 people have low vision, with country and regional variation ranging from 2.4 to 5.5. These figures - the first global estimates since the early 1990s - are the best achievable scientific estimates of the global burden of visual impairment and are the result of new studies carried out in nearly all WHO regions (*Figure 2.1*), which have substantially updated the epidemiological data.

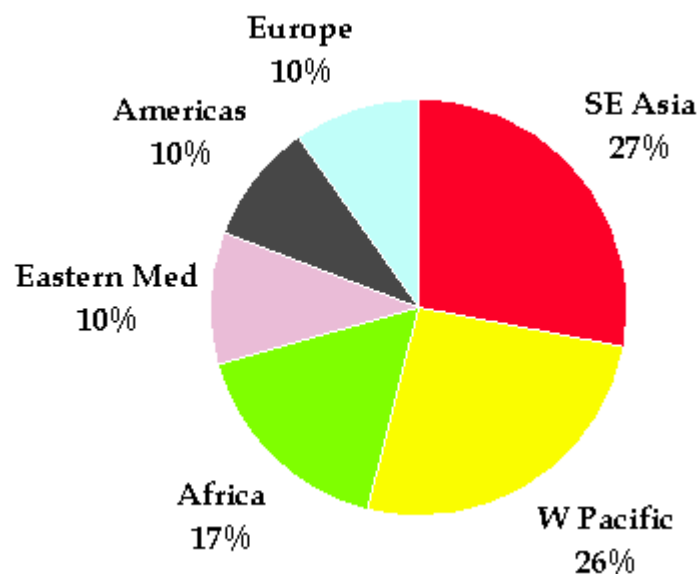


Figure 2.1: Global estimate of visual impairment by WHO region

2.3.2 Causes of Visual Impairment Worldwide

Except for the most developed countries, cataract remains the leading cause of blindness in all regions of the world. Associated with ageing, it is even more significant as a cause of low vision.

Glaucoma is the second leading cause of blindness globally as well as in most regions, with age-related macular degeneration (AMD) ranking third on the global scale. However, in developed countries, AMD is the leading cause of blindness, due to the growing number of people over 70 years of age.

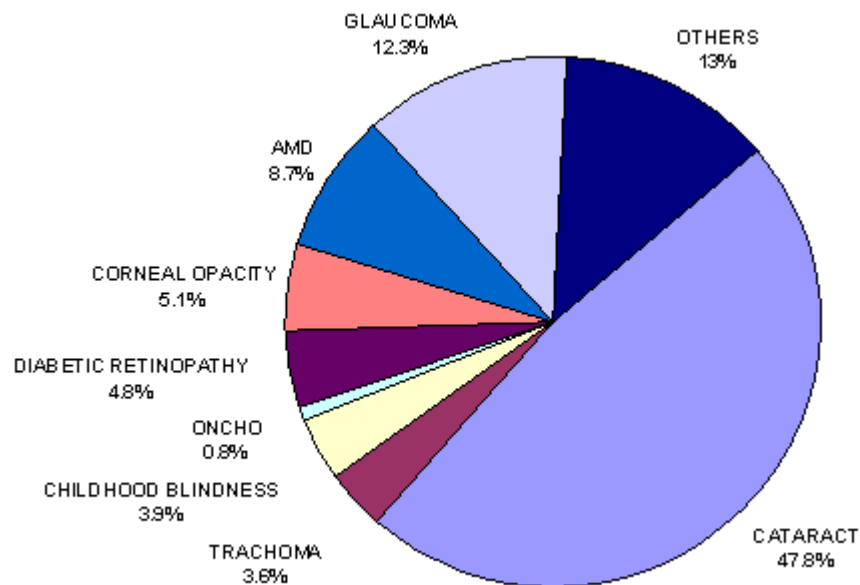


Figure 2.2: Global causes of blindness as a proportion of total blindness in 2002

The causes of blindness that can potentially be prevented and/or treated include cataract, glaucoma, corneal opacity, diabetic retinopathy, onchocerciasis, childhood blindness and trachoma. WHO estimates that,

up to 75% of all blindness is avoidable. However, the proportion of the specific causes of blindness varies considerably from region to region, depending on local circumstance. Only about half the cases of childhood blindness are avoidable.

2.4 Visual Impairment in the UK

2.4.1 Numbers of Visually Impaired in UK

Nigel Charles, working for the Royal National Institute for the Blind (RNIB), has estimated the number of visually impaired older people in the UK [36] based on two UK national prevalence studies [37] [38] and the 2001 Census. About half of visually impaired older people fall into the category of mild visual impairment (6/12 – 6/18). The other half has a moderate to severe visual impairment ($VA < 6/18$).

In 2003 there were 370,561 people registered as sight-impaired or severely sight-impaired in England, Wales and Scotland about 68% of whom were over 75 years of age [36]. The RNIB estimates that as many as two out of three people who are eligible to be registered as blind or partially sighted are not registered and those suffering visual impairment could be as many as 1,066,740 [39]. There is strong evidence to suggest that this under-registration is especially common in patients with treatable conditions such as glaucoma and diabetic retinopathy [40-42]. Charles estimated the number of people over 64 with varying levels of visual impairment. These estimates are shown *Table 2.1*.

Estimates of numbers of people in age groups >64 years with visual impairment of varying severities. Numbers include those with treatable and untreatable visual impairments (95% confidence interval)				
Visual Acuity	Age Group			Row Total
	65-74	75-84	85+	
Mild Visual Impairment	503,000 (450,000-568,000)	335,000 (308,000-364,000)	214,000 (206,000-223,000)	1,052,000 (964,000-1,155,000)
Moderate & Severe Visual Impairment	276,000 (173,000-375,000)	279,000 (234,000-322,000)	301,000 (269,000-339,000)	856,000 (676,000-1,036,000)
All VA <6/12	779,000 (623,000-943,000)	614,000 (542,000-686,000)	515,000 (475,000-562,000)	1,908,000 (1,640,000-2,191,000)

Sources: NDNS for those aged 65–74 years; MRC for those aged 75 years and over, Census 2001
Note: See text for definitions of visual acuity

Table 2.1: Estimates of numbers of people visually impaired over the age of 64.

2.4.2 Causes of Visual Impairment in the UK

In the prevalence report by Tate et al [43] (*Figure 2.3*) they looked at five surveys to estimate the causes of visual impairment in the UK. One study was based on a sample covering the whole of Great Britain [37], the others were from selected regions: two in London [44, 45] and two in Leicestershire [46, 47]. All except one [46] were concerned with the elderly (people aged 65 and over).

The prevalence report stressed the difficulty in directly comparing the results from these studies as they all used different definitions of disease and cut-off points for the group being investigated e.g. Visual acuity (VA) was <6/18 in the MRC Assessment Trial and < 6/12 in the North London Study. This report cites cataract, refractive error and age related macular degeneration as the major causes of visual impairment in the elderly with the contribution from age related macular degeneration rising with

increasing age. The data from the MRC Assessment Trial also showed that the relative contribution of different causes varies by level of impairment, with cataracts being most important for low vision, and age related macular degeneration for blindness.

Although glaucoma and diabetic retinopathy make minor contributions to visual impairment in the prevalence report, not all the studies included additional tests such as fields, or fundusoscopic examination. It is therefore possible that the contribution of glaucoma and diabetic retinopathy to visual impairment may have been underestimated. In the North London Study (which did include a detailed assessment for glaucoma), definite glaucoma was the reason for VA <6/12 in either eye in 3% and possible glaucoma in 7%. By contrast, the prevalence of cataract associated with VA < 6/12 in one or both eyes was 30% and refractive error was 9%.

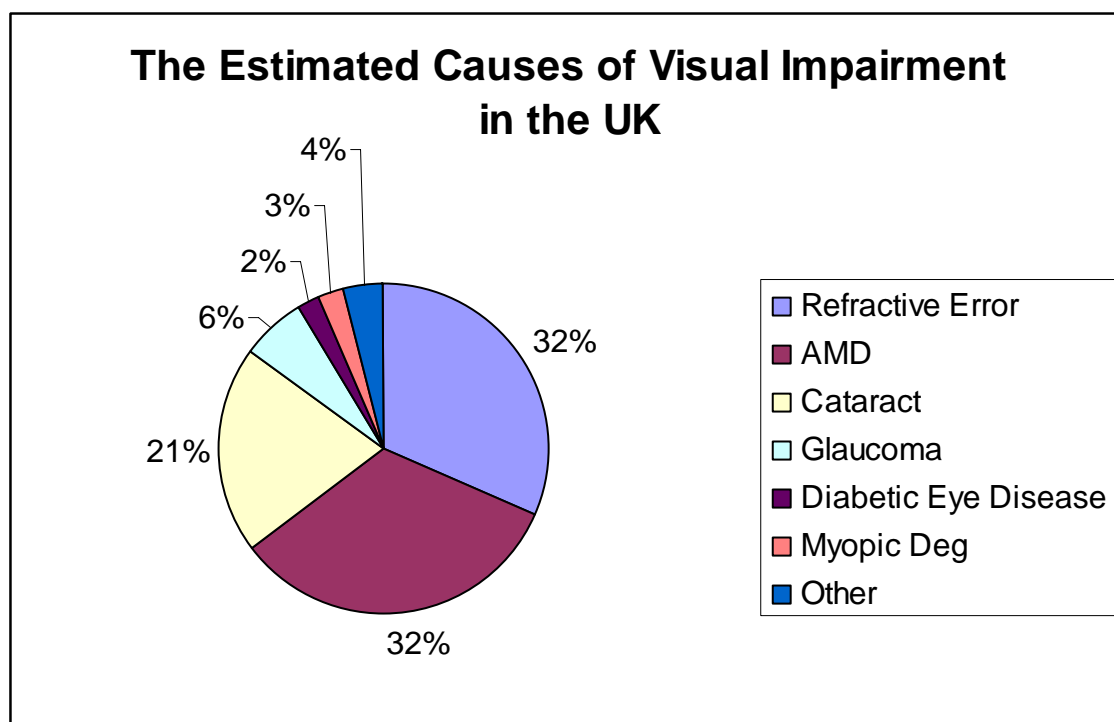


Figure 2.3: Estimated Causes of Visual Impairment in the UK [43]

3.0 GLAUCOMA

3.1 Classification of Glaucoma

3.1.1 Definition of Glaucoma

Glaucoma is a group of progressive disorders resulting in loss of visual field and damage to the optic disc. Weinreb et al [48] state the biological basis of glaucoma is not fully understood and the factors contributing to its progression are not yet fully characterised. These factors will vary depending on the type of glaucoma. If not treated, all forms of glaucoma will lead to blindness.

3.1.2 Different Types of Glaucoma

Glaucoma can be classified in many different ways. By primary or secondary conditions, by age of onset (adult or juvenile), or by open and closed angles. Primary glaucoma can have elevated pressures or more rarely, a pressure within normal limits (normal tension glaucoma). In secondary glaucomas, the main aqueous outflow route becomes obstructed and results in elevated intraocular pressure. *See Figure 3.1.* for the different types of glaucoma.

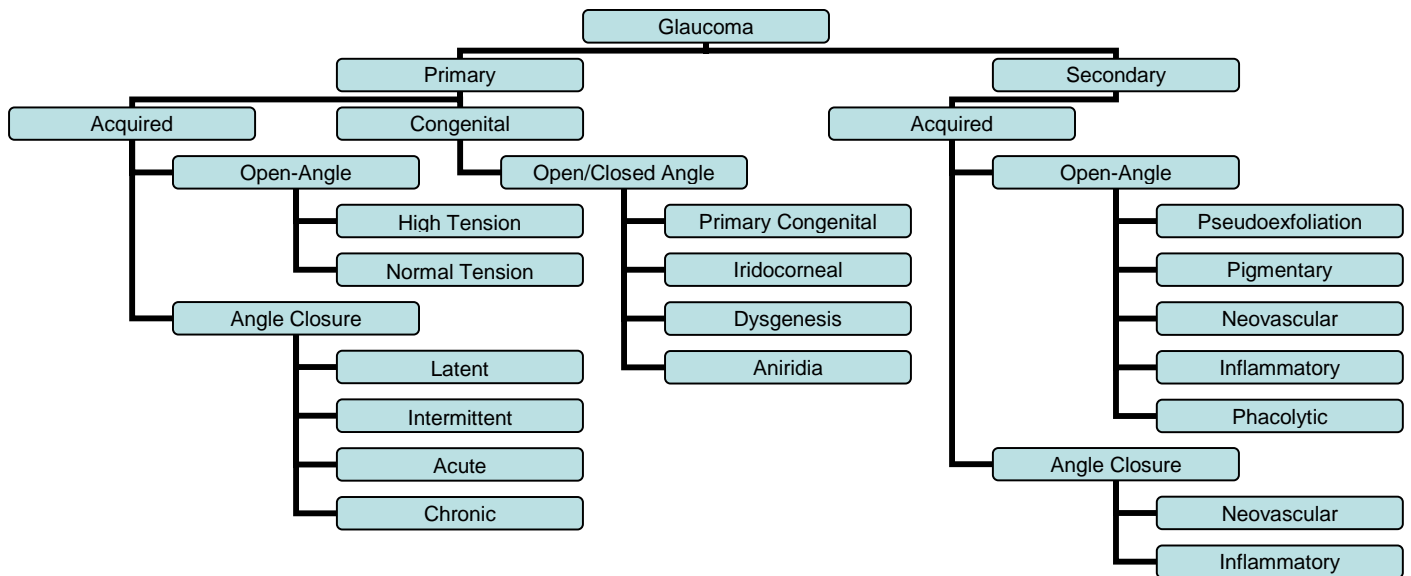


Figure 3.1: Glaucoma Classification

3.2 Glaucoma Prevalence

In 1996 Quigley [49] looked at glaucoma prevalence worldwide. This study was a paper review of 111 published prevalence reports. Reliable reports were then used to estimate prevalence of open-angle glaucoma and angle-closure glaucoma by ethnic group and by age. He estimated that 66.8 million people worldwide had open-angle glaucoma and angle-closure glaucoma in equal numbers. An additional 6.0 million people were estimated to have secondary glaucoma. This estimate was larger than the 5.2 million estimated by Thylefors, and Negrel [50] as this earlier study was based mainly on blindness surveys which may have understated glaucoma since visual impairment is only noticeable in the later stages of the disease. Quigley argued that by these estimates

glaucoma is, or soon will be, the second largest cause of bilateral blindness in the world after cataract [51] and the recognition of this should stimulate interest in better case detection. In 2006 Quigley [52] again looked at the data on glaucoma prevalence worldwide as a further 34 new surveys had appeared. As a result of this research, he proposed a standardised definitional structure of primary open-angle glaucoma (POAG) and angle-closure glaucoma (ACG) in order to compare prevalence across glaucoma studies. He concluded that by 2010, 60.5 million (95% CI: 44.4, 85.4 million;) people will have POAG and ACG. Over 8.4 million (95% CI: 6,012,805 to 12,331,095) people will be bilaterally blind from primary glaucoma in 2010, rising to 11.1 million (95% CI: 7,947,390 to 16,230,278) by 2020 and that glaucoma will be the second leading cause of blindness worldwide.

3.2.1 Primary Glaucomas

In *Figure 3.1* we can see the different types of glaucoma for reference purposes, but the main focus in this thesis will be on primary open-angle glaucoma. Quigley found that in people originating from Europe, primary open-angle glaucoma (normal and high tension) accounts for most of the disease (Prevalence 2.42% for over 40 years) [49]. When looking at primary glaucoma he based his primary open-angle glaucoma and primary angle-closure glaucoma estimates on 19 studies of prevalence. As a result, he concluded that primary open angle glaucoma is 11.4 times

more prevalent than primary angle closure glaucoma in European derived populations (Prevalence 0.2% for over 40 years).

Quigley and Vitale have shown the impact in terms of numbers with open-angle glaucoma *Figure 3.2*. It can be seen that the prevalence of primary open-angle glaucoma increases after the age of 40 and that approximately 85% of all glaucomas are found in people aged 60 and above.

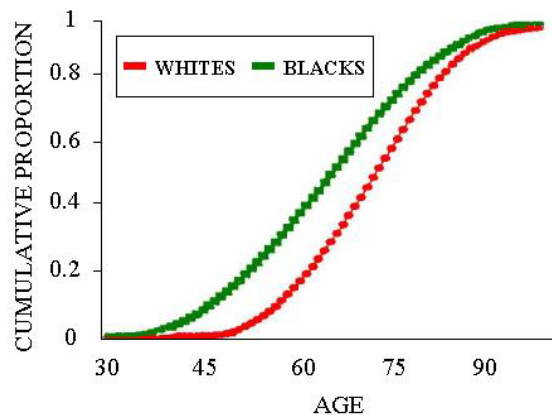


Figure 3.2: Cumulative proportion of open-angle glaucoma (OAG) incidence in white and black persons in a simulated United States population in which derived incidence values are applied to a cohort of persons ranging in age from 30 to 100 years of age [53].

Rudnicka et al [54] carried out a Bayesian meta-analysis looking at age, gender and race. Forty-six published studies were examined. *Table 3.1* summarizes their estimated prevalence of POAG by age and racial group. The Table shows that the difference in prevalence of POAG between racial groups varied with age. In the 40 to 49 year olds, the prevalence of POAG in black populations was approximately 7 times higher than the prevalence in white populations, whereas by age 80 to 89

years the prevalence was approximately 2.5 times higher. The prevalence in Asian populations was similar to the prevalence in white populations at ages 40 -69: thereafter it is relatively higher in white populations.

Age Range (yrs)	Predicted Prevalence of OAG (95% CrI)		
	White	Black	Asian
30-39	-	1.8 (1.2 – 2.7)	0.4 (0.3 – 0.6)
40-49	0.4 (0.3 – 0.6)	2.9 (1.9 – 4.4)	0.6 (0.4 -1.0)
50-59	0.8 (0.5 – 1.2)	4.6 (3.1 – 6.8)	1.0 (0.6-1.6)
60-69	1.6 (1.1 – 2.5)	7.2 (4.9 – 10.6)	1.6 (1.0 – 2.4)
70-79	3.3 (2.2 – 4.9)	11.2 (7.6 – 16.1)	2.5 (1.6 – 3.8)
80-89	6.6 (4.4 – 9.7)	16.9 (11.7 – 23.8)	3.8 (2.3 – 5.9)
90-95	10.8 (7.2 – 15.8)	22.5 (15.7 – 31.2)	-

Table 3.1: Rudnicka et al's estimated prevalence according to age and race. [54]

3.3 Primary Open-Angle Glaucoma (POAG)

Primary open-angle glaucoma is a bilateral, usually asymmetric, progressive condition, which is characterized by an open, normal-looking drainage angle and a glaucomatous optic nerve head appearance in the absence of other causative pathology. A visual field defect may or may not be present. The disease is asymptomatic until its advanced stages when the patient may be aware of peripheral field loss. In the early stages, field defects are overlooked within a binocular field.

There is a lack of consistency in how POAG is defined [55-57] and reviews of the literature have been unable to detect a trend in the

proportion of articles providing a uniform definition for glaucoma. The examination of a patient to confirm or exclude the presence of POAG includes assessment of intraocular pressure, optic nerve appearance and visual fields. As the use of technologies for patient examinations become more widespread and the understanding of the disease improves the definition will continue to evolve.

3.3.1 Nature of Disease

Without adequate treatment, glaucoma can cause severe visual disability and ultimately blindness. The disease results in a progressive loss of the field of vision but it is only in the later stages, when there is advanced damage to the optic disc, that there is loss of central visual acuity. The best estimates we have suggest that it takes 5 years or more to progress to blindness if untreated [58]. Due to the slow progression of the disease individuals do not notice any problems in the early stages. Over 95% of referrals for suspected glaucoma are made by high street optometrists of people attending for refraction for new glasses [59, 60]. In some cases, at the time of referral, patients are often blind or severely visually impaired. Unfortunately, once the damage has occurred to the nerve it cannot be reversed. Early detection and treatment of the disease are beneficial in preserving vision [61, 62].

3.3.2 Glaucoma Case Finding

There is wide agreement that detecting glaucoma sooner and instituting appropriate interventions earlier improves results in preservation of visual outcome and contributes significantly to controlling incidence as the population ages [63]. Official population screening programmes for glaucoma are desirable,[64] but their economic feasibility is debatable [65]. For screening to be effective the test must not only have satisfactory sensitivity and specificity but it must also be cost effective. In the absence of such a test, the usual method for detection of individuals with glaucoma has been periodic comprehensive eye examinations.

3.4 Cost of Glaucoma

Guide Dogs for the Blind (GDBA) produced a document on the cost of blindness within this they look at the cost of glaucoma [66]. Based on the age specific prevalence rates provided in the North London Eye Study [44] and Royal College of Ophthalmology (RCO) estimates for the working age population [67] , GDBA estimated that there were 2.2 million glaucoma sufferers in the UK in 2002. The annual total costs associated with this condition are presented as a base case, low and high case scenario and in both aggregate and per patient annual cost terms. The results of this analysis are summarised in *Table 3.2*.

	Total Non-Treatment Costs	Treatment Costs	Total Annual Costs
<i>Total Annual Cost</i>			
Base Case	£24,732,543,737	£2,252,182,797	£26,952,901,559
Low Case	£14,901,930,774	£1,139,872,034	£16,041,802,808
High Case	£34,524,816,738	£3,690,752,717	£38,215,569,455
<i>Per Patient Annual Cost</i>			
Base Case	£11,161	£1,016	£12,178
Low Case	£6,725	£514	£7,239
High Case	£15,581	£1,666	£17,246

Table 3.2: Annual Glaucoma Costs – UK (2002) [66].

As these results indicate total annual costs ranged from £16 billion to £38 billion. Their reference case estimate was £27 billion. A delay in the onset of significant visual loss has implications not only for patients but also for government expenditures

While treatment costs may increase as a result of an early intervention programme (particularly targeted at groups at risk from developing glaucoma), the ability to delay onset of visual loss is associated with potential cost savings to the government in terms of reducing the number of people receiving government benefits associated with visual impairment and blindness.

3.5 Glaucoma Knowledge

In the reading of this literature there is an important distinction to make between those who have heard of glaucoma and those who have

knowledge of the disease. In this thesis “awareness” is used for those who have heard of glaucoma and “knowledge” for those who know more about glaucoma than just the name.

Rosenstock’s study [4] on health behaviour and health belief suggests that a patient’s knowledge concerning the value of regular eye care may play a significant role in seeking eye care. Javitt [68] suggests that eye health education could be used to help prevent blindness. With only 50% of the glaucoma diagnosed in western populations [69, 70] it has been questioned whether it is lack of awareness and knowledge about the disease that could be the root cause [61] . There have been a number of studies looking at glaucoma knowledge in different countries (see *Table 3.3*). Some studies look at different eye diseases, including glaucoma, and some look specifically at glaucoma. In the cases where authors have not graded knowledge, the liberal definition has been taken that at least one correct answer represents some knowledge.

All the studies are different and there is no standardised method for assessing glaucoma knowledge. Two studies [71, 72] used focus groups and in-depth interviews to look at knowledge and attitudes making it difficult to quantify levels of knowledge. Of the studies using questionnaires, all were different in length, depth and question type. All these factors have to be considered when comparing the results.

Table 3.3 shows that levels of awareness and knowledge are varied in different populations. This is highlighted in Costa's study [73] which looked at two different urban populations (one in Brazil and one in United States of America) and found that knowledge of glaucoma varied greatly between the two areas. Levels of health education could be a reason for low knowledge in different areas and Juzych [74] showed that people with low health literacy had low levels of knowledge. Looking only at the population-based studies, the proportion who had heard of glaucoma was as low as 0.32% and 2.4% in rural India [75, 76] and as high as 93% in Australia [77] and 78% in Hong Kong [78]. This highlights the importance of knowledge surveys for specific countries and specific populations within the same country.

Ten of the studies commented on age. Of these, 4 studies [77-80] found the younger the age group, the more knowledgeable they were. Three studies found age not to be a factor [73, 81, 82] and one study [75] found knowledge increased trend in those aged 30 and above. Two studies were specific about which age ranges were the most knowledgeable: Gasch [83] found a trend in that the 50 -79 year olds to be most aware and Landers [84] found the 40 – 59 year olds most knowledgeable. In general the young and elderly had the least knowledge which might indicate a hill of knowledge in the middle age groups however the evidence is insufficient to be sure of a consistent pattern. It is more appropriate that each population group is treated individually in this respect.

In studies from Australia [77, 85] and Switzerland [81] females were found to be more informed than males. Livingston [85] found 59% of females to be aware of glaucoma compared to 41% of males and Mansouri found 26% of females compared to 14% of males to be aware. In Lau's study [78] he states it was the males that were significantly more knowledgeable, however the males were more aware (females odds ratio (OR) 0.67(0.51-0.88)) but of those that were aware it was the females that had more in-depth knowledge (females OR 1.65 (1.13-2.42)). Gender is clearly a contributing factor in some populations but none of the studies discuss or give reasons for this difference.

There is a striking difference between studies in the developing and developed world. The studies in the developing world showed extremely poor knowledge: Balo [86] reported 30% had heard of glaucoma, while Dandona [75] and Krishnaiah [76] reported 2.4% and 0.32% had heard of glaucoma. This low level of knowledge is highlighted in Dandona's study where 73% had heard of cataract but only 2.4% of glaucoma. In contrast the number of people who had heard of glaucoma in the developed world was much higher. The lowest number who had heard of glaucoma was 67% in Cross's UK study [71] and goes up to 93% in Attebo's Australian study [77]. Costa's study [73] looks at knowledge levels in two different populations of glaucoma patients, one in the USA (developed) and one in Brazil (developing). The patients in the USA were found to be more

knowledgeable about their disease than their counterparts in Brazil. This follows the previously stated trend shown in the other studies.

Having heard of glaucoma does not imply in-depth knowledge. We can see from the study by Attebo [77] that 93% had heard of glaucoma but only 29% of these participants had any detailed knowledge. Livingston's study [85] which was also from Australia and Lau's study in Hong Kong [78] showed similar results. How in-depth knowledge is defined is an important consideration together with how much knowledge we would like the general population to know. Do we need everyone to be a glaucoma expert or is it sufficient for people to know that glaucoma is a blinding eye disease that can be prevented if you have your eyes tested? It is obviously more desirable for patients to have greater knowledge about the disease and its treatment regimes after diagnosis. This is shown to be the case in Livingston's study [85] where 67% those who were diagnosed with the disease had a reasonable understanding. In Danesh-Meyer's study [87] where the participants were split into three groups (established glaucoma, newly diagnosed glaucoma and controls), established patients were the most knowledgeable and controls least. Controls understandably knew little about treatment. Although 95% of controls knew glaucoma was an eye disease 78% incorrectly thought it could be cured.

There is no clear difference between clinic-based and population-based studies: both types of study show a range of glaucoma awareness. In-

depth knowledge does tend to be marginally higher in the clinic-based studies which is to be expected as most of these studies consisted of some if not all patients who had already been diagnosed with glaucoma. This evidence supports the fact that patients who are in a clinic setting are already accessing services and are more likely to be “illness aware”.

From *Table 3.3* it can be seen that there is a clear lack of UK data in either a clinic-based or population-based form. As discussed earlier it would be wrong to make assumptions about the level of knowledge in the UK from studies from different populations. Cross et al [71] has carried out the only UK-based study and this is based on a specific African Caribbean population living in Birmingham. The study suggests a low level of knowledge within this targeted population but because it uses qualitative methods it is not possible to quantify in-depth knowledge.

In their conclusions, all studies have highlighted a need for health education to be improved. They also indicate a need for increased knowledge about eye disease and glaucoma independent of the level of awareness in their study. There is an underlying assumption that the more aware and knowledgeable the population is, the more motivated they will be to access eye services and reduce preventable blindness in their populations. Three of the studies [84, 88, 89] state that the education campaigns need to target the young and be carried out in schools. Two studies [82, 88] highlight a need for high risk groups to be educated. Three studies state a need for better communication between

eye services and the general population. This was a prominent point in those studies undertaken in developing countries [76, 86] but was also highlighted in one study from a developed country [71].

Thus the largest difference in awareness and knowledge is between the developed and the developing countries. Within populations the main differences in knowledge are in age and sex.

Author/ Year	Location	No of Participants	Age of Participants	Clinic Based/ Population Based	% Heard of Glaucoma	% Knowledge of Glaucoma	Other Comments
Attebo et al (1997)[77]	Australia	3574	49 and above	Population Based	93%	29% (of those who had heard of glaucoma)	
Lau et al (2002)[78]	Hong Kong	1269	40 and above	Population Based	78%	10%(of those who had heard of glaucoma)	Based on people with vision less than 6/18. Females more likely to have heard than Males.
Michielutte et al (1984)[82]	North Carolina	368	14 and above	Population Based	---	>70%	They use a complicated scoring which complicates an understanding of the results. They acknowledge that the results could be misinterpreted.
Hovenaars et al (2005)[79]	Maastricht - Netherlands	166	---	Clinic Based	---	90%	Patient based study.
Livingston et al (1995)[85]	Australia	1711	40 and above	Population Based	70%	22%(of those who had heard of glaucoma)	Divided into two groups those with Glaucoma N=25 and those not previously diagnosed. Of those with the disease 67% had reasonable understanding. Women were more aware than men.
Pfeiffer et al (2002)[80]	Germany	2742	14 and above	Population Based	75%	51%(of those who had heard of glaucoma)	Interviews were face-to –face in peoples homes.
Mansouri et al (2006)[81]	Switzerland	502	35 to 70	Population Based	---	24.7% Knew Glaucoma was an eye disease	Cluster random sample. Don't give a reason why. This will reduce power. All participants answers were rated for accuracy by a senior Ophthalmologist. When adjusting for variables awareness was independent of education.
Gasch et al (2000)[83]	Massachusetts	1197	16 and above	Clinic Based	72%	---	Of the 72% 80% of these were diagnosed with glaucoma. They

							did not look at detailed glaucoma knowledge.
Ellich et al (2007)[72]	Baltimore	86	40 and above	---	---	---	Focus groups looking at beliefs about eye examinations in African Americans. Focus groups aren't analysed in correct manner. Saw vision as part of normal aging process. Number not reported on who had heard of glaucoma. Focus on risk factors. Participants recognized race as a risk factor but only when asked. They had heard about the increased risk to African-Americans but were unsure about its credibility.
Danesh-Meyer et al (2008)[87]	New Zealand	408	50 and above	Clinic Based	----	81%	Split into 3 groups. 208 established glaucoma, 100 newly diagnosed and 100 controls undiagnosed but selected in a clinic setting ie: came with somebody who had glaucoma.
Noertjojo et al (2006)[88]	Canada	882	20 and above	Population Based?	----	40%	Randomly selected 8 Rural communities then asked Family Practitioners in these areas to participate. Each doctor was given a randomization scheme to select participants. Women were 1.6 times more likely to be familiar about glaucoma. This was similar with AMD & Cataract in this population. Very little was known about risk factors.
Paczka et al	Mexico	492	----	Clinic Based	44.7%	29.9%	Article in Spanish only abstract

(2006)[89]							available in English.
Landers et al (2002)[84]	Sydney-Australia	240	40 and above	Clinic Based	82%	35%	Participants were patients who attended a general A&E Dept. Women were more knowledgeable.
Cross et al (2007)[71]	Birmingham - UK	48	Mean age of 48	---	67%	---	Semi-structured Interviews and focus groups. No way of quantifying in-depth knowledge.
Balo et al (2004)[86]	Lome - Togo	767	20-65 years	Population Based	30%	25% (of those who had heard of glaucoma)	Article in French only abstract available in English.
Juzych et al (2008) [74]	Michigan	204	18 and above	Clinic Based	---	---	Found that patients with poor health literacy knew less about glaucoma.
Costa et al (2006) [73]	Brazil/USA	283	50 and above	Clinic Based	---	56%	Patient based study comparing two different urban areas.
Dandona et al (2001) [75]	Hyderabad - India	1843	15 and above	Population Based	2.4%	86.7%(of those who had heard of glaucoma)	73% were aware of cataract. Awareness of all eye disease was higher in those 30+.
Krishnaiah et al (2005)[76]	Hyderabad - India	5573	15 and above	Population Based	0.32%	---	Only 8 respondents knew that visual loss from glaucoma is permanent. Questionnaire was based on Dandona's but was different,

Table 3.3: Papers on Knowledge of Glaucoma.

4.0 RESEARCH METHODS

4.1 Introduction

This chapter will briefly look at the differences between qualitative and quantitative research methods. It will then look in more depth at the research methods I have employed in my research: in-depth interviews, focus groups and questionnaires.

4.2 The Difference Between Qualitative and Quantitative Research

The main differences between Qualitative and Quantitative research can be seen in *Table 4.1*. Qualitative research relies on interpretive or critical approaches to social science and follows a non-linear research path. It emphasises conducting detailed examinations of cases that arise in the natural flow of social life and trying to present authentic interpretations that are sensitive to specific social-historical contexts.

Quantitative research relies on a positivist (rather than an interpretive or critical) approach to social science.

Quantitative Research	Qualitative Research
Test hypothesis that the researcher initiates	Capture and discover meaning once the researcher becomes immersed in the data
Concepts are in the form of distinct variables	Concepts are in the form of themes, motifs, generalisations and taxonomies
Measures are systematically created before data collection and are standardised	Measures are created in an <i>ad hoc</i> manner and are often specific to the individual setting or researcher
Data are in the form of numbers from precise measurement	Data are in the form of words and images from documents, observations and transcripts
Theory is largely causal and is deductive	Theory can be causal or non-causal and is often inductive
Procedures are standard, and replication is assumed	Research procedures are particular, and replication is very rare
Analysis proceeds by using statistics, tables or charts and discussing how what they show relates to hypotheses	Analysis proceeds by extracting themes or generalisations from evidence and organising data to present a coherent, consistent picture

Table 4.1: The key differences between qualitative and quantitative research

Quantitative methods generate a mass of numbers that need to be summarised, described and analysed. Characteristics of the data may be described and explored by drawing graphs and charts, doing cross tabulations and calculating means and standard deviations. Further analysis would build on initial findings, seeing patterns and relationships in the data by performing multiple regression analysis, or an analysis of variance. Advanced modeling techniques may eventually be used to build sophisticated explanations of how the data addresses the original question.

Qualitative methods generate a mass of words by interviews, focus groups or observational data that need to be described and summarised.

The question may require the researcher to seek relationships between various themes that have been identified, or relate behaviour or ideas to biographical characteristics of respondents such as age or gender.

4.3 Qualitative Research Methods

In the area of health care, social factors are as important as clinical ones in determining who suffers from disease, who presents for treatment and how they manage treatment regimes. The aim of qualitative research in this field is to understand the motivations and perceptions of target groups and how they impact on health behaviour.

The use of qualitative study methods can be expensive and time-consuming. Planning is often a balancing act between design and resources, in other words what would be nice to do and what is feasible with the resources at hand. Resources include the time available for the project, the financial resources, and the talent and creativity of people in the study team. Design includes: which methods will be used, the number of investigations to be carried out and the complexity of the analysis once the data has been collected.

4.3.1 Sampling Strategies

Sampling strategies of in depth interviews and focus groups follow the same principles. Newman shows the different types of sampling see *Table 4.2*.

Type of Sample	Principle
Haphazard	Get any cases in any manner that is convenient
Quota	Get a present number of cases in each of several predetermined categories that will reflect the diversity of the population using haphazard methods
Purposive	Get all possible cases that fit particular criteria, using various methods
Snowball	Get cases using referrals from one or a few cases, and then referrals from those cases
Deviant Case	Cases that differ from dominant pattern (specific purposive sampling)
Sequential	Get cases until there is no additional information
Theoretical	Get cases that will help reveal features that are theoretically important about a particular topic

Table 4.2: Sampling Strategies. [90]

Most focus groups and in-depth interviews use a theoretical sampling model. It is called theoretical sampling because it is guided by the researchers developing theory. Participants are selected to reflect a range of the total study population or to test a particular hypothesis. Variety is important. Class, ethnicity and other variables should be considered. Sample sizes are not determined by hard and fast rules, but by other factors such as feasibility. Ideal focus groups and interviews would continue until the same themes are continually being discussed

and no new ideas are coming forward. This is called “saturation” but is not always possible with limited time and financial constraints.

Mays and Pope have written excellent short guides for health professionals on using qualitative research methods [91-95]. Their recommendations for in-depth interviews and focus groups form the basis of the information given below.

4.3.2 In-Depth Interviews

There are three types of interviews: structured, usually with a structured questionnaire, with fixed standardised questions. e.g. “Is your health: excellent, good, fair, or poor?”; semi structured, based on a loose structure consisting of open-ended questions that define the area to be explored. e.g. “What do you think good health is?”, and; in depth interviews which are completely unstructured than this and may cover one or two issues in great detail. The questions asked are based on what the interviewee says and consist mostly of clarification and probing for details.

Qualitative interviewers try to be interactive and sensitive to the language and concepts used by the interviewee, and they try and keep the agenda flexible. They aim to go below the surface of the topic being discussed, explore what people say in as much detail as possible, and uncover new areas or ideas that were not anticipated at the outset of the research. It is

vital that interviewers check that they have understood respondents' meanings instead of relying on their own assumptions. This is particularly important if there is obvious potential for misunderstanding.

Good questions are the key to good interviews. Patton [96] states that good questions in qualitative interviews should be open ended, neutral, sensitive, and clear to the interviewee. He lists six types of questions that can be asked:

1. Behaviour or experience
2. Opinion or belief
3. Feelings
4. Knowledge
5. Sensory experience
6. Background or demographics.

Questions usually follow a pattern starting with questions that can be easily answered. These are shown in Table 4.3:

Type of Question	Description
Opening	Participants get acquainted and feel connected
Introduction	Begins discussion of topic
Transition	Moves smoothly into key questions
Key	Obtains insight on areas of central concern in the study
Ending	Helps researchers determine where to place emphasis and brings closure to the group

Table 4.3: In-depth interview questions pathway.

Most interviewees are willing to provide the kind of information the researcher wants, but they need to be given clear guidance. It is possible to collect data even in stressful circumstances. The less structured the interview, the less the questions are determined and standardised before the interview occurs. Most qualitative interviewers will have a list of core questions that define the areas to be covered. The order in which questions are asked will vary, as will the questions designed to probe the interviewees' meanings. During the course of a qualitative study, the interviewer may introduce further questions as they become more familiar with the topic being discussed.

Successful qualitative interviews require considerable skill by the interviewer. For the interviewee to feel comfortable and able to speak freely it is important that anonymity is ensured. i.e. in the case of a patient they need to know that what they say will not affect their treatment or doctor-patient relationship. To ensure this, it is of benefit for the interviewer to be impartial to the findings.

Interviewers need to be aware of their directiveness, whether they are asking leading questions, and if clues are being picked up or ignored.

Whyte devised a six point directiveness scale to help researchers guide their own interviewing technique: [97]

- | | |
|--------------------|---|
| Least
Directive | 1. Making encouraging noises |
| ↓ | 2. Reflecting on remarks made by the informant |
| | 3. Probing on the last remarks made by the informant |
| | 4. Probing an idea preceding the last remark by the informant |
| ↓ | 5. Probing an idea expressed earlier in the interview |
| Most Directive | 6. Introducing a new topic |

The point is not that non-directiveness is always best, but that the amount of directiveness should be appropriate. Some interviewees are more talkative than others and it is important that the interviewer maintains control of the interview. Patton provided three strategies for maintaining control [96]:

1. Knowing the purpose of the interview – what it is you want to find out.
2. Asking the right questions to get the information you need.
3. Giving appropriate verbal and non-verbal feedback.

There are some common pitfalls that have been identified by Field and Morse [98]:

1. Interruptions from outside e.g. telephones
2. Competing distractions e.g. children
3. Stage fright for interviewer or interviewee
4. Asking interviewee embarrassing and awkward questions
5. Jumping from one subject to another
6. Teaching
7. Counselling
8. Presenting one's own perspective, thus potentially biasing the interview
9. Superficial Interviews
10. Receiving secret information
11. Translators i.e. being inaccurate

Awareness of these pitfalls can help the interviewer develop ways of overcoming them.

4.3.3 Focus Groups

Focus groups are a form of group interview that capitalizes on communication between a number of research participants in order to generate data. Group interaction is an integral part of this method and rather than the interviewer asking each person to respond to a question in turn, people are encouraged to talk to one another: asking questions, exchanging anecdotes and commenting on each others' experiences and points of view.

Focus groups are good for:

- looking at a range of ideas or feelings around a topic
- understanding different perspectives between groups or categories of people
- uncovering factors that influence opinions, behaviour or motivation
- pilot-testing ideas, materials, plans or policies
- researchers who need information on quantitative data already collected

They should not be used if:

- you want to educate people
- you want to come to a consensus
- other methodologies can produce better information
- other methodologies can produce the same quality of information more economically
- you cannot ensure the confidentiality of sensitive information

Focus group studies can consist of anything between half a dozen to over fifty groups depending on the aims of the project and the resources available. Most studies involve just a few groups and some combine this method with other data collection techniques, such as in-depth interviews. Most researchers recommend aiming for homogeneity within each group in order to capitalise on peoples' shared experiences. However it can also be advantageous to bring together a diverse group (i.e. from a range of professions) to maximise exploration of different perspectives within a group. However it is important to be aware of how hierarchy within a group could inhibit participants.

There are four main components to a good focus group.

1. Purpose:

- What do you want to find out?
- Ensure that a Focus Group is the right tool to use

- Be clear on the area for discussion
- Stay focused around this area
- Do not be tempted to move into other areas of interest

2. Target Group

- Ideal group number is between 6-8 people who share a common theme
- Have one-to-one contact asking them to participate in order to encourage participation
- Send a letter to confirm date, time, place
- You may need to provide an incentive to encourage people to participate

3. Environment

- Talk to people in the target group
- Ask what would be a suitable location
- Ask about a suitable time
- Check out extra needs e.g. parking or childcare
- Sessions should be relaxed and comfortable
- Refreshments and sitting in a circle can help to establish the right atmosphere

4. Skilled Moderator. A good moderator has the following skills:

- Listening

- Communication
- Group inclusion
- Summarising
- Time management
- Flexibility
- Handling difficulties

Analysis

The analysis of in- depth interviews and focus groups is the same. It is widely accepted that audio taping interviews and focus groups is preferable to note taking. Notes can be made as well as taping but should be done after interviewing, so the interviewee has the interviewer's full attention. Interviews should be transcribed and include as much detail as possible, including long silences, err's and mmm's.

Grounded Theory is the traditional way of analysing qualitative data and was developed by the sociologists Strauss and Glaser. [99] Its analysis is inductive, in that the resulting theory emerges from the data through a process of rigorous and structured analysis. At the heart of grounded theory is the constant comparative method. Concepts or categories emerging from one stage of the data analysis are compared with concepts emerging from the next. The researcher looks for relationships between these concepts and categories, by constantly comparing them, to form the basis of the emerging theory. The researcher continues this

process of comparison until they reach ‘theoretical saturation’, i.e. no new significant categories or concepts are emerging.

A more recent approach to qualitative analysis is the Framework Technique[100] (see *Table 4.4*). The framework technique shares many common features with grounded theory but the benefit of this method is that it provides systematic and visible stages to the analysis process. The method is both flexible and systematic and encourages objectivity and maximum use of the data.

Framework Technique	
1. Familiarisation	Reading and re-reading the transcriptions
2. Identifying a Thematic Framework	Condense data into categories
3. Indexing	Codes systematically applied to the data
4. Charting	Re-arranging the data according to the thematic content in a way which allows for a cross case and within case analysis
5. Mapping and Interpretation	Interpretations and recommendations

Table 4.4: Framework Technique[100]: Similar to that developed by the Independent Research body, Social and Community Planning Research, now the National Institute for Social Research. [101]

To be able to comment on themes we look at the following:

- Frequency – some attention. Remember sometimes key insights might be said only once in a series of groups or interviews. You have to know enough about the subject to spot a gem.
- Specificity - more emphasis given to comments that are specific and provide detail e.g. from experience.

- Emotion – weight given to comments that show emotion, enthusiasm, passion or intensity.
- Extensiveness – how many different people said the same thing. One person may say something often this is frequency, different people in different groups saying the same

As in all qualitative analysis, deviant case analysis is important: i.e., attention must be given to minority opinions and examples that do not fit with the researcher's overall theory. In general it is not appropriate to give percentages in reports of qualitative data, and it is important to distinguish between individual opinions expressed and group consensus.

4.4 Quantitative Research Methods

A range of quantitative research methods are used in social sciences. The most common are based on: the analysis of existing statistics; specially commissioned surveys of samples of the population, or investigations using controlled conditions.

Quantitative techniques involve the use of standardised and scheduled questionnaires, rather than the more open methods discussed in 4.3. Methods of analysis rely on manipulation of numerical data, rather than textual analysis. Survey research concentrates on generalities and on 'normality' (in a statistical sense) and divergence from it.

4.4.1 Questionnaires

In designing a questionnaire that is reliable, valid and acceptable to respondents, great care must be taken over wording, response formats and the order of items. Difference in wording can produce very different responses. Questions can be about demographic facts (age, gender, number of children), knowledge, behaviour or attitudes, and the researcher must consider whether the item is an appropriate indicator for the kind of information sought. A key consideration is the target population, and the instrument designed must be pre-tested with members of the target population before the survey. Newman [90] shows us the steps involved in survey research. *Figure 4.1*

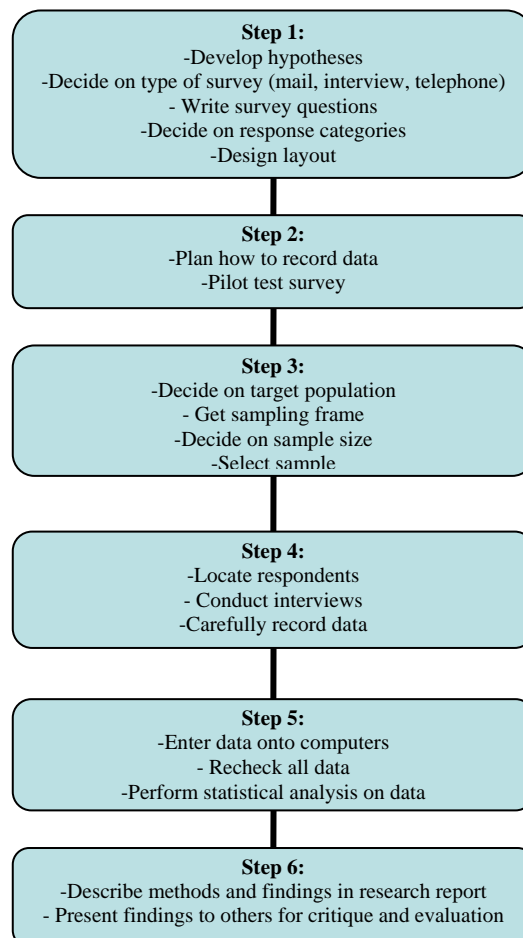


Figure 4.1: Steps in the process of survey research [90]

When asked a question in a questionnaire it is hoped that a respondent will answer accurately and honestly. Green & Browne [102] list below the psychological processes that can inhibit accuracy and honesty:

- Misunderstanding the question: simple misunderstanding of the intention behind a question is very common.
- Inability to recall: Asking people to recall events and moods over a long period can be an extremely difficult task.
- Guessing: The answers to many questions may not be recalled with perfect accuracy so respondents may use a variety of strategies to 'guess' what they consider to be the 'right' answer.
- Mapping the answer onto the response alternative: Response formats are unlikely to correspond exactly to our respondents' individual mental representations, and 'true' answer can often become lost in translation.

The second problem for questionnaire design arises from a variety of biases that occur when answering questions:

- Satisficing: This occurs when respondents give what they consider a 'satisfactory' rather than optimal answer. A common example of this is the tendency to select the first response alternative that seems reasonable, rather than considering all the options and then choosing.

- Social desirability and faking good: Respondents are likely to want to present the best version of themselves to the world in a questionnaire. This can lead to extreme bias when we ask about sensitive subjects such as socially undesirable behaviours.
- Deviation and faking bad: In some situations a respondent may perceive it advantageous to appear in as bad light as possible.
- Acquiescence: Respondents are more likely to agree than disagree with statements in a questionnaire.
- End-avoidance and positive skew: These problems arise when respondents are asked to provide an answer in some form of continuous scale. End avoidance occurs because respondents often do not like to choose extreme answers. Positive skew occurs because respondents tend to favor more positive responses, leading to response distributions that do not centre on the middle option.

4.4.2 Good Questions

The wording of a question is extremely important. To achieve objectivity it is important not to lead the respondent into giving the answer we would like to receive. Qualities of a good question include:

- Neutral wording: Value-laden questions produce biased responses.
- Avoids asking two or more questions at the same time.
- Accommodates all possible answers.

- Has mutually exclusive response choices, so that a single answer cannot fall into more than one category.
- Provides unambiguous differences between response choices.
- Produces variability of responses: When a question produces no variability, we learn little and cannot perform statistical analysis on the item.
- Does not make unwarranted assumptions.
- Does not ask questions where the respondent has to guess (satisfice) the correct answer.
- Does not imply a desired answer.

4.4.3 Pre-testing

It is important to try out a questionnaire on representatives of the target population. If there are problems they will show up here and can be dealt with before the main survey.

Mail, telephone and face-to-face are the three main ways questionnaires are administered. Each has advantages and disadvantages. It is important to choose the correct method for your target population. Table 4.5 looks at the different features.

Features	Mail	Type of Survey	
		Telephone	Face-to-Face
<i>Administrative Issues</i>			
Cost	Cheapest	Moderate	Expensive
Speed	Slowest	Fastest	Slow - Moderate
Length	Moderate	Short	Longest
Response rate	Lowest	Moderate	Highest
<i>Research Control</i>			
Probes Possible	No	Yes	Yes
Specific Respondent	No	Yes	Yes
Question Sequence	No	Yes	Yes
Only One Respondent	No	Yes	Yes
Visual Observation	No	No	Yes
<i>Success With Different Questions</i>			
Visual Aids	Limited	None	Yes
Open-ended Questions	Limited	Limited	Yes
Contingency Questions	Limited	Yes	Yes
Complex Questions	Limited	Limited	Yes
Sensitive Questions	Some	Some	Some
<i>Sources of Bias</i>			
Social Desirability	No	Some	Worst
Interviewer Bias	No	Some	Worst
Respondents Reading Skills	Yes	No	No

Table 4.5: Features of different types of survey. [90]

4.4.4 Mail and Self-Administered Questionnaires

Advantages: researchers can give questionnaires directly to respondents or mail them to respondents. This type of survey is the cheapest method and can be conducted by a single researcher. A researcher can send the questionnaire to a wide geographical area and the respondent can complete it at a time that is suitable to them. Mail questionnaires offer anonymity and avoid interviewer bias.

Disadvantages: Since people do not always complete mail questionnaires the biggest problem is low response rate. Returned questionnaires can

take a long period of time to trickle in. Researchers cannot control the conditions under which the questionnaire is completed and cannot guarantee that it is only filled in by one individual. Incomplete questionnaires can also cause problems. Mail questionnaires limit the kinds of questions that can be asked, e.g. visual and complex questions do very poorly in mail questionnaires. Mail questionnaires are also unsuitable for anyone who is illiterate or near-illiterate. They are unlikely to complete them and those who do probably misunderstand the questions and so the answers are meaningless.

4.4.5 Telephone Interviews

Advantages: the telephone interview is a popular survey method because about 95% of households can be reached by telephone. An interviewer calls a respondent (usually at home) asks questions and records the answers. The sample is taken either from lists, telephone directories or by random digit dialing. In general, telephone interviewing is flexible and has a lot of the strengths of face-to-face interviewing but for half the cost and time. Interviewers control the sequence of questions and can, if appropriate, use some probes. A specific respondent is chosen and will answer all the questions alone.

Disadvantages: the method is relatively expensive and long interviews are not practical. Respondents without telephones are impossible to reach and a good response rate is dependent on dedicated interviewers

giving call backs. Refusal rates for interviews can be high due to the increased amount of telephone market research. The use of an interviewer reduces anonymity and introduces potential interviewer bias. Open-ended questions are difficult to use and questions using visual aids are impossible.

4.4.6 Face-to-Face Interviews

Advantages: face-to-face interviews have the highest response rate and permit the longest questionnaires. They have all the advantages of telephone interviews and the interviewers can also observe the surroundings and use non-verbal communication and visual aids. Well trained interviewers can ask complex questions, and use extensive probes if appropriate.

Disadvantages: face-to-face interviews are expensive due to training, travel, supervision and personnel. Interviewer bias is also greatest in face-to-face interviews. The appearance, tone of voice and wording of questions by the interviewer may affect the respondent. In addition interviewer supervision is less than for telephone interviews in which supervisors monitor by listening in.

5.0 PATIENT AWARENESS

5.1 Introduction

In Chapter 3 I addressed the nature of glaucoma. The loss of central visual acuity is typically the last occurrence in advanced glaucoma where progressive deterioration of visual field typifies the advance of optic nerve damage. The burden of visual handicap from the disease in the community is therefore much larger than blindness registration would suggest. If the effectiveness of interventions to prevent the progression of glaucoma is to be assessed, it is important to make a clear assessment of the social burden of handicap from the disease. At present there is only one other significant field-dependent measure of social function and that is the DVLA test for fitness to drive.

As discussed in Chapter 3, Section 3.3.1 the disease is insidious in nature, and relatively slow in progression, taking 5 years or more to progress to blindness if untreated [58]. Many adaptive processes take place in individuals to cope with any visual handicap. Unlike many diseases, coping strategies that evolve to overcome visual handicap in glaucoma are dysfunctional as they conceal the existence and progression of the disease. It is very difficult to estimate the social burden of the disease. How much less productive is an accountant with 50%

visual field loss? How much more care is required for an elderly individual living alone with 50% visual field loss?

A large body of work has been done to investigate the value of questionnaires in quality of life assessments of individuals with glaucoma [103]. The questionnaires have, however, focused on activity-related functions. Few have explored the important aspects of recreation and motivation highlighted by Owen and Herse [104]. None have explored the state of mind of the individual, although it is known that individuals with low vision are frequently depressed [105, 106]. In addition, the possibility of altered behaviour patterns to avoid stigma associated with being visually handicapped [107] has not been addressed.

There was a clear need for qualitative research to address the wider issues of glaucoma and the effect this disease has in the community. It was hoped that such research would highlight new areas requiring intervention (e.g. expansion of support mechanisms for sufferers) and facilitate the better assessment of intervention strategies involving the identification and treatment of cases within the community.

This study intends to address these issues in a qualitative fashion as described in Chapter 4, Section 4.3.

5.2 Methods

In-depth interviews and focus groups were chosen as described in Chapter 4 because these methods, used in the correct environment, can allow individuals to express freely their feelings and opinions. They can give a deep insight into individual patients' opinions on living with glaucoma and its accompanying restrictions.

5.2.1 Sampling Strategy

A purposive sampling strategy was used as described in Chapter 4 *Table 4.2*. Patients of both sexes and a wide range of ages with moderately severe or severe primary open angle glaucoma were recruited by an ophthalmologist. Patients had to have definite reproducible field loss totaling the equivalent of a quadrant or more on Humphrey field analysis in at least one eye. Twenty-eight patients were sampled from two hospitals; one was a specialist urban eye hospital and the other a District General Hospital. All participants gave written consent and this sampling strategy was approved by the Moorfields Ethics Committee. *Figure 1* shows the age range and gender of all study participants.

Study Participants		
Gender	Male	14
	Female	14
Age Range	>70	12
	60-69	7
	50-59	5
	40-49	3
	<40	1
	Total	28

Table 5.1: - Study Participants.

5.2.2 Interviewing techniques

Of the 28 participants, 20 were interviewed with in-depth one-to-one interviews and 8 took part in focus groups. These were used to create an open discussion on living with glaucoma. Both techniques investigated functional and dysfunctional strategies of glaucoma patients. Key prompts are listed in *Table 5.2*, which shows the main areas we wanted to cover. They were used to guide the interviews and focus groups where necessary.

Key Prompts	
Referral <ul style="list-style-type: none">• Trigger of referral• Mode of referral (GP, optician, self)• Symptoms	Daily Coping <ul style="list-style-type: none">• Difficulties• Use of aids• Help from others
Response to Diagnosis <ul style="list-style-type: none">• Awareness of condition• Change in attitude• Change in lifestyle	Light <ul style="list-style-type: none">• Effect of darkness• Effect of bright light
Major Changes <ul style="list-style-type: none">• DVLA• Blindness Registration• Things patients could do 1yr ago and cannot do now	Interest in Glaucoma <ul style="list-style-type: none">• Awareness• Knowledge• Need to tell others• Need to understand condition
Treatment <ul style="list-style-type: none">• Application• Side effects• Surgery advice	Hopes and Fears <ul style="list-style-type: none">• What do patients want for the future?• What are their personal hopes and fears?

Table 5.2: Key prompts

5.2.3 Analysis

All interviews and focus groups were taped and transcribed for more detailed analysis. Written consent for this was obtained from all participants. The interviews were analysed using the framework technique described in Chapter 4 *Table 4.4*. This method of analysis was used because it is both flexible and systematic and encourages objectivity and optimum use of the data. As discussed in Chapter 4.2 primary analysis was carried out by the principal investigator and validated by the social researcher as recommended by Armstrong et al [108]. All quotes displayed in the results have the interview/focus group number brackets at the end of the quote.



Figure 5.1: In-depth Interview in Leeds – Taking Consent.

5.3 Key Findings

5.3.1 Triggers

There were triggers common to all patients such as blurred vision and flashes. These triggers were not recognized as symptoms of the disease by the patient. The majority of patients who recognized a problem with their sight did so while doing close work such as reading, photography and drawing or by playing ball games like tennis. Although clinicians are aware that triggers such as glare, pain and haloes are experienced, it is suggested in glaucoma there are no recognized clinical symptoms of the disease [109-111].

“I noticed my glaucoma first, er, when reading in bed. I was reading along, and out of context this word Fra Sinatra, leapt out at me. I went back and had a look and it was Frank Sinatra. The NK had vanished.” (I1)

“I do machine work, I noticed like a zigzag of lightning, across the centre of the left eye.” (I2)

5.3.2 Unexpected Diagnosis

Early signs were seen as normal illness and were put down to tiredness, age, the need for a new ophthalmic prescription or previous eye conditions such as conjunctivitis. Some patients assumed visual disability was a result of pre-existing disease from childhood or birth.

“I was never honestly aware, at any time, oh, until a slight mistiness when I was em, reading. I read a lot, you see, and I began to notice that it was getting a little misty, and I thought, at that time – well, it’s time, I wore glasses.” (I6)

Diagnosis came as a surprise to nearly all patients as few had noticed any symptoms and hardly anyone had noticed any visual field loss. For some patients diagnosis was the first indication that there was something wrong with their eyes. Some patients did not recognise a problem even after diagnosis.

“I was very surprised by the results of the field test, actually, because I always thought I had good peripheral vision...and I have never noticed any deterioration of that.” (I5)

“The top right of my visual field, was really so dark, it had gone, you see, and they were afraid of it coming down to tunnel vision. But as far as I was concerned, I was seeing perfectly normally.”(I6)

All patients did their own field tests with their fingers to draw comparisons between clinical findings and their own experiences. The shock of diagnosis was heightened by patients' limited knowledge of glaucoma and its potential seriousness.

“Well I suppose it knocked me back a bit at the time. Because I didn't really know what it was, or what it was going to do.” (I4)

5.3.3 Treatment

In some cases, side effects from drops made vision much worse and strict treatment regimes restricted lifestyle. This resulted in many patients being only part compliant with their treatment.

“...it made an enormous difference, when I turned over to these new drops. First of all I could see much better, the worst effect of pilocarpine, is that you can't see in the dark. Unless the light is good , you really, you're very very handicapped...I'm also relieved from the tyranny of

putting your drops in every six hours, for the last couple of months, life has been very much better.” (I8)

“...at some stage, I think I was doing about fourteen times a day drops, you know.”(I2)[

5.3.4 Driving

The loss of ability to drive was similarly reported as a significant disability for many. Several participants reported that they had tried to hold on to their driving licences for as long as possible, using a variety of strategies to reduce the chance of vision problems causing an accident. These included avoiding driving in the dark, or only driving routes they knew well. However, for some, the loss of a licence had not been as devastating as they had predicted:

“Losing your driving licence – that is the pits. I thought that was the worst thing that could happen to me – it’s not, as I’ve discovered” (G2)

Again, the quality of the external environment shaped the experience of loss. One man described his regret at losing his car:

"I used to be like a car fanatic, I used to love the car! I find that hard, it's like relying on other people, and I don't like that, sort of a burden on people ... although I'm getting used to it now!" (I11)

He went on to comment that being unable to drive would be less of a burden 'if public transport was to run on time'. For a largely urban sample, with access (if limited) to public transport, using a car (or the legitimate right to do so) may have more symbolic than practical importance, as a marker of independence.

5.3.5 Reading

For many, problems with reading were the greatest hardship of impairment, and several talked about fears of no longer being able to read:

"I can't tell you how important reading is to me. And as I get older, it gets more important. [If it deteriorated] I wouldn't care about living any more, to be honest with you." (I6)

"For me, being so young, it's really difficult, because I used to read a lot. Now I'm limited, I just have to read for an hour, two hours a day and I miss that a lot, because I love reading." (G1)

Occupational context meant that for the young woman quoted above, limiting reading to two hours a day was a restriction, as she was studying for a degree, so there was no additional time available to read for pleasure. Clearly, for those in different circumstances, being able to read for only one or two hours a day might not be at all disabling.

Thus an apparently mundane everyday mistake takes on a particular significance in the context of maintaining a valued social role. Similarly, many participants talked about the problems of seeing ground level activity, and therefore accidentally kicking household pets, or bumping into small children. For one woman, this was the ‘worst thing’ about living with glaucoma:

“That’s the worst thing, I was always bumping into my children and I was always losing my children, you know I’d be walking, and I’d say ‘where’s Rosie?’ and Rosie, well she was right beside me!” (G1)

For women, especially, the need to involve male partners in tasks formerly considered ‘their work’ was difficult and potentially guilt-inducing:

“And he’s very tired at the weekend, so it’s very difficult. I will go to the supermarket, but he has to come and collect me. But em, it is an extra sort of burden” (G1)

Other participants reported that diminishing visual ability had not had a serious impact on their quality of life, despite meaning that driving was no longer possible, and gardening and other household tasks were made more difficult. One man, having described how glaucoma had stopped him driving, and thus travelling to see his family or going for days out in the country, said he was not worried about the long term implications of being 'dependent':

“Knowing my wife, I mean I’ve got no worries in terms of what she would do for us in any case ... I wouldn’t have any problems ... [I’d] be looked after.” (I2)

In general, the men in the sample were less likely to express fears about their dependence on partners and other family members:

“I rely very much on my wife, who knows that in a strange environment I cannot walk quickly and she’ll walk in front of me (G2)”

One young woman, a student from a large family, did describe the help she received from relations (that she expected as a matter of routine) in getting to college, but others in the group pointed out that this was a solution not open to many in the relatively more isolated families typical of English cities:

“My sisters and aunts help, when anybody has time”

“So you’re really dependent on your family or friends ... well my mother and father have now died, and there’s no one, my sisters are [abroad] I can’t suddenly ring up and say ‘well can you just help me get to the supermarket!’” (G1)

For most participants, though, there was a tension between preserving independent mobility and being able to manage day to day activities at a practical level. Accounts of everyday life thus stressed that one ‘coped’ – but often at a cost.

5.3.6 Cost of Coping

Given that many participants had coped, perhaps unconsciously, with diminishing visual ability before their diagnosis, most had found a variety of ways of minimising the impact of symptoms on everyday life. These included double-checking the position of objects (such as cups before pouring water), making sure kitchen implements or tools were always left in the same position, and improving household lighting. Of course such strategies are to some extent the actions many people without glaucoma might take to reduce clumsiness, or cope with the ‘normal’ bodily deterioration of advancing age, so were not in themselves evidence that ‘something unusual was happening’ pre-diagnosis. Once their eyesight difficulties had been labelled specifically as ‘glaucoma’, participants could be more explicit about referring to these as coping strategies. In the

focus groups particularly, participants discussed the techniques they had developed to manage everyday tasks:

“A real classic is when you drop something, and it just goes bouncing off, and then its down on the floor, sort of scanning – you have to learn to scan”

“That’s it, scanning –“

“Like a radar, sort of”

“Yeah, like a robocop!” (G2)

Participants in the two focus groups also shared tips with each other about how to cope with glare from lighting and reductions in visual fields, such as: writing with thick felt pens; wearing hats outdoors to reduce the impact of the difference between lighting indoors and outside; and investigating the possibility of voice-recognition software. In hearing other peoples’ accounts of symptoms, some participants re-labelled experiences specifically as the effects of glaucoma:

“I’m wondering, listening to you, because I have a job to recognise textures ... and I couldn’t see details like where buttons were on garments ... so maybe that’s the glaucoma.” (G2)

Patients felt they coped but at a cost. Independence was highly prized. Reliance on others caused inner conflicts even if the dependence was on a spouse. Loss of a driving licence was seen as a major loss of

independence. Patients hold on to their driving licence for as long as possible and justify to themselves that they are safe on their previous driving record. Patients would also claim to be safe because they didn't drive at night or only on short journeys, proving that patients know they may be unsafe at times but are not ready to admit it.

"...whatever the DVLA test might say, I know perfectly well that I can see, er, well enough to drive. I mean, I'm a responsible citizen, if I thought for a moment I was a danger to everyone or anybody else, I'd stop driving, but I'm sure I am not." (I8)

"...although Ian told me to give up, I mean they told me like June, I didn't actually give up till about August, because I had the car, and it was sitting on the drive." (I11)

Patients who were still working found they had little energy left for family and leisure time. The decision to give up or to continue work was a major decision as patients struggled with the fight for independence or the chance to have more time and energy with families. For some of the younger patients, giving up work was not seen as an option, adding more stress.

"So I do it as normal. And I do as much as I can. Then I go home, and I'm absolutely exhausted." (G1)

“...’cause at the end of the day I do need my job, ‘cause I’ve got a wife and two kids to support, so you know, I do need that job.” (I11)

“My work has definitely been affected, I mean, I’ve been going through the last three years, thinking can I really continue?” (FG1)

5.3.7 Perceptions of Blindness

The other aspect of ‘coping at a cost’ is the balance to be maintained between the practical issues of mobility, while projecting an image of an independent person. People with glaucoma may not present to the outside world as ‘disabled’, in that there may be no visible signs of impairment. In Goffman’s [112] phrase, the stigma is ‘discreditable’ rather than ‘discredited’, and many participants in this study valued being able to present as ‘normal’. However, this of course brings practical problems when routine expectations of ability (e.g. that you will see small children in a crowded train station, or the floor buttons in a dim lift) are not met. In the focus group discussions particularly, participants talked about these tensions between wanting to present ‘normality’ and managing with tasks such as mobility:

“People say you look normal”

“yes, you don’t necessarily look it yourself, but you look normal (laughter)”

“And when its good you actually feel –“

“Yeah”

“Relatively normal. And so you think, I can do it”

“Yeah, yeah”

“And you can act normal” (G1)

“Going somewhere really dark, I sort of get panicky, in case I don't see something or someone and walk into them, 'cause they don't know what you're suffering with and I don't want to sit down and have to explain to someone what's wrong with me.” (I9)

Deciding whether, and how to, use a 'white stick' was a key example for many. Although there were recognised advantages (e.g. that it enabled you to gauge the depth of steps, and drew attention to hazards that may not be within eyesight), it also brought added practical problems - one more thing to carry from the shops, for instance, as shopping has to be done on foot. However, it was also a very potent symbol of disability, which was rejected by many. One solution to the dilemma was to carry the stick, in case it was needed – but not visibly:

“I've got a white stick - in my handbag! When I use it, I have enough vision that I can see people looking at you quite openly ... and then people offer you seats on the bus or whatever, you get a little bit more attention, so I get embarrassed.” (G1)

Similarly, walking with a guide could lead to feelings of stigma:

“When I usually walk with my sister, people think that I don’t see anything at all, and you know, they’ll start staring at me, I feel uncomfortable” (G1)

This example reflected the lack of understanding about the effects of glaucoma that some participants felt was a problem. Just as they had not understood much about the disease pre-diagnosis, they noted that the misconceptions of acquaintances could present problems. One man talked about a tennis partner who slowed down the game, although this actually made the ball harder to see. Others talked about the way in which friends would point out the easily seen sights (e.g. a mountain, trees in the distance) but not the hazards out of their field of vision, such as unexpected steps, kerbs or street furniture. Even professional helpers could lack understanding of the impact of glaucoma:

“After six months on the waiting list I had a rehabilitation worker ... she said ‘what is the problem with your eyes?’ I mean this was because I was registered blind, and I just said ‘oh its glaucoma’ and I nearly dropped dead when she made the next comment – ‘Oh, is that all?’” (G1)

Conflicts were created by not wanting to draw attention to oneself, keeping white sticks in handbags or only wearing dark glasses when absolutely necessary, and wanting their condition to be understood. If patients could not see people greeting them in the street, they wanted

people to realise that it was the result of the disease and not that they were being rude.

“I’ve got a white stick, in my handbag, at least, and when I use it, I have enough vision that I can see people look at you – openly.” (G1)

“I don’t want people to treat me differently. Being aware that I have a problem, but what I’m very worried about, is that people would see that stick, and assume – like I always did, a white stick means total blackout.” (G2)

The specific diagnosis of glaucoma was also unexpected in terms of lay ideas about sight disability. Many reported that they had not heard of glaucoma, and that their diagnosis was the first encounter they had with the term. For some respondents, blindness was considered to be a disability one either had or did not have, and the concept of a disease that might gradually cause sight loss did not fit with their pre-existing ideas about eye health:

“Well I suppose it knocked me back a bit at the time. Because I didn’t really know what it was, or what it was going to do.” (I4)

“[The diagnosis] put me down, depressed me terribly. I’d never considered it you see. I’d heard of glaucoma, but I didn’t know, for

instance, it could creep up on you without you realising. 'Cause it's, it's so silent, so without warning it strikes, doesn't it?" (I6)

"I'd never heard of glaucoma - always thought vision [was an] open/shut affair" (I2)

To some extent, this lack of awareness of the gradual effects of glaucoma reflected general perceptions of 'blindness' and what it meant to be blind. When participants who still had some functional sight talked about their ideas of people with partial sight or blindness, they talked largely of those with no vision at all. Concepts of what blindness meant were often based on individuals they had known or known about. Images of 'blind people' were a mixture of sympathy or pity for the extreme dependence that was seen to result from blindness, and admiration of achievements in the face of disability.

"When I was about four, I used to run into the house of a man next door... and that man was completely blind. His wife got him up, I suppose, dressed and changed him. He sat there all day long. He never went out." (I2)

"I fear for them [blind people], quite frankly. I see them going along the road, and I'm afraid for them." (I6)

The other side of this image of victims was one of heroic endeavour, and overcoming the disability.

“And he used to sing solo, in concerts, and he read the words with his left hand, and the music with his right, in Braille. Which is pretty awe-inspiring, I think.” (I11)

“How David Blunkett manages to be Secretary of State for Education, I’ll never know. Absolutely amazing, without being able to see” (I8)

One exception was a man with diabetes, for whom eye disease was a perceived risk, who recalled being surprised by field test results at the time of the diagnosis, but saw the diagnosis as, in retrospect, predictable. This participant also reported less extreme perceptions of what blindness might mean, and an image more rooted in a social model of disability:

“I’ve listened for years to the talk on the radio programme for blind and partially sighted people ... it’s a good programme... This programme helped, because many people are living quite normal lives” (I5)

Given the low reported level of awareness of glaucoma, and of the range of eye problems expected by most respondents as part of ‘normal life’, most of those interviewed reported that particular symptoms were not a trigger for their referral, unless they had occupations which demanded reliance on eyesight.

5.4 Discussion

In Zola's study on triggers he suggests that people accommodate symptoms until something breaks down or overrides the accommodating factor [113]. This could be the interference with interpersonal relationships, the disruption of normal work roles or the occurrence of a life event. For most health problems this is functional, as many resolve without medical intervention, and others are no harder to treat once advanced. This is not the case with glaucoma. Starting therapy as early as possible in the disease process is important, as once damage occurs, it is irreversible. Treatment for glaucoma, if diagnosed early, can arrest glaucomatous optic nerve damage or delay it so that satisfactory vision is retained for the patient's lifetime [114]. This study found few triggers for early referral. People accommodated well to deteriorating sight and explained symptoms to be everyday sight problems (e.g. need of a new prescription, tiredness or they were seen as the unavoidable result of aging).

In a society in which a large proportion of the population has corrected vision, minor eyesight problems are seen as 'normal illness', easily accommodated until it becomes obvious that 'something unusual is happening'. Clinically, visual function is assessed in a number of ways, including acuity, contrast sensitivity, colour perception and field of vision. For most of the population, visual acuity is the key aspect of eyesight that impacts on awareness of 'visual ability'. Diseases, such as glaucoma, in

which other functions are affected like peripheral vision, without loss of acuity, are unlikely to prompt self-referral until late in the disease process.

Nearly all participants in this study were 'surprised' by the diagnosis of glaucoma. They reported little or no knowledge about glaucoma pre-diagnosis. This was echoed in their accounts of discussing their condition with friends, acquaintances and even professional workers post-diagnosis. Many were faced with perceptions that glaucoma was exclusively a disease of old age, or that it was a minor condition which would not cause disability. This ignorance and preconceptions may also be reflected in the wider population.

After diagnosis, everyday experiences of sight disability could be re-framed in retrospect as symptoms and warnings of potential future disability. The 'biological disruption' [115] of an unexpected diagnosis was then reassessed within the patients' current strategies for coping and their concerns about the future.

'Independence' had different meanings depending on gender, age and other social factors. For the younger women particularly in this study, decreasing independence and inability to shop, look after the children and work was reported as keenly felt disabilities. For some other participants (particularly the older men, and one woman who lived with her extended family), there were routine expectations that others (wives, relatives) would help as an extension of their normal roles, and the lack of

independent mobility was consequently not reported as disabling. The meaning of independence has been shown to be rooted in wider cultural values. Charmaz, [116] in her study of the impact of chronic illness on self identity, noted that 'residuals of the Protestant Ethic' pervaded the notion of a valued self for the participants in her North American study. Hard work and independence were the essence of self worth, and those with chronic illness faced a double burden of the impact of disease and a diminished sense of self. Some participants in this study made reference to similar ideas, with working roles (both paid and unpaid) clearly crucial to a sense of self. However, the impact of symptoms is highly dependent on the specific social circumstances, and 'independence' is viewed differently depending on the point in people's life-cycle, gender and support networks.

Minor environmental changes, such as improving the level of household lighting, could effect dramatic changes in ability to cope. Although most participants were positive about the treatment they received from their hospital specialists, they were less positive about help they had received from rehabilitation services, such as those offered to help people use white sticks or consider household aids. That the focus groups in this study were used to discussing strategies for coping, and to exchanging ideas for managing symptoms and treatment regimes, suggests that there is a need for better access and awareness for this kind of help.

In 1970, Scott wrote about the role of experts in turning those who do not see well into 'blind men' [117]. For many of the participants in this study who still had some functional vision, images of 'blindness' were rather negative, resonating with broader social stereotypes of blindness – namely that the only roles open were 'victim' or 'hero'. These roles were mainly formed from past interactions or memories of other blind people. Glaucoma, because its onset is insidious, can involve the sufferer in a long (often permanent) transition from taking sight for grant to the problematic persona of a blind person. Many participants resisted registering as blind or displaying themselves as blind people by using a white stick in public. Despite resisting the stigmatised label, many nevertheless reported significant current disabilities, concerns about future prognosis, and social difficulties arising from the routine expectation that they had 'normal' eyesight. To some extent, this reflects the impoverished models of blindness available – few can be heroes, and few wish to be victims. Instead, many adopted a strategy of 'coping at a cost': maintaining a valued self image of 'normally sighted person' (within that large range in a population where many have corrected vision), while developing practical and social strategies to maintain physical mobility and social roles.

The reasons why glaucoma goes undetected include: failure of people to have regular sight tests; deficiencies in glaucoma testing at a primary care level; and referral criteria. This inevitably results in many borderline cases being overlooked [64]. Screening may be seen as a solution to

early detection but at present there is no single test sufficiently valid for the identification of sufferers at primary screening. To justify the cost and patient anxiety involved in referral for secondary examination by a consultant ophthalmologist, a single acceptable, cheap, robust and valid test for glaucoma which is able to reliably detect early stages of the disease is required.

The International Glaucoma Association has shown that in the UK the highest proportion of appropriate referrals to the hospital eye service is made by optometrists via the general practitioner [118]. Optometrists initiate over 90% of referrals for chronic glaucoma [59]. The public needs to be made aware of the importance of regular eye tests especially among those with a family history of glaucoma. We need to move away from the common opinion of sight tests only being required for people who have an ophthalmic prescription.

Free sight testing was withdrawn in the United Kingdom on 1st April 1999. This raised concerns that the introduction of a sight test fee would deter people, especially the elderly, from having routine sight tests. In the year following the introduction of charges it was reported that referrals to Bristol Eye Hospital had dropped by 15% [119] suggesting that the sight fee had deterred people. However on closer examination of the data people, had rushed to obtain free eye testing before the implementation of the fees. On re-analysing the data omitting the figures relating to the

year before charges were introduced, no change in trend is evident [120] [121]. Therefore the cost of testing is not responsible for people not coming forward for regular sight tests.

Since completing this study, additional literature has been produced on the subject of vision and depression. Brody *et al* have looked at depression, disability and age-related macular degeneration [122]. Walker *et al* have looked at psychological distress in relation to vision and cataract [123]. Two studies, Evans *et al* [124] and Hayman *et al* [125] have looked at general visual impairment and depression. All studies indicate that people with visual impairment are more likely to experience problems with functioning which in turn can lead to depression. Visually impaired people are more likely to be depressed and this is independent of any physical impairment. This study found reduced vision to have a major impact on managing everyday tasks and although we did not specifically explore depression and state of mind with these patients it is clear that glaucoma patients with severe visual loss could be prone to suffer from depression as with other visual diseases.

5.5 Conclusion

Participants in this study reported low levels of awareness of glaucoma pre-diagnosis. After diagnosis, glaucoma presented them with a range of problems in managing everyday life. The majority of glaucoma patients felt the public misunderstood the impact of the disease on people's lives

due to the general lack of awareness surrounding glaucoma. Increased awareness of glaucoma may increase the number of patients identified before the disease has progressed. This awareness may also help to provide better understanding for those who are already diagnosed as having glaucoma.

6.0 PILOT STUDY

6.1 Introduction

As a result of the study of patients with glaucoma discussed in Chapter 5 and from other studies carried out by fellow researchers [126, 127] it was felt that a public health campaign to raise awareness about glaucoma was the appropriate next step. In order to enable the creation of a public health campaign, it was necessary to decide on a target population, and then find out what they read, watched and listen to, before going to the expense of a full public health campaign it was important to determine crude knowledge levels and to see if a basic press and radio advertisement would have any effect. The following pilot study was therefore undertaken.

Objective: To determine whether a public health package on glaucoma reaches its target population.

6.2 Study Location

Two populations were chosen to enable the study to make generalisations about the findings: the Isle of Wight and Southall, Ealing. Both were deemed to be good choices for such a study because they had each had a single community radio station, local press and an established community network. The Isle of Wight is a mainly Caucasian population with an age bias towards the elderly. Southall, Ealing is a multicultural, diverse urban population with a substantial number of people of Indian origin.

6.3 Methods

The health intervention comprised two components: an interview on local radio and an advertisement in the local paper. Our target population was people aged 45 and above who were resident in either location. We had ethical approval for the study from Moorfields Eye Hospital Ethical Committee and the Isle of Wight, Portsmouth & South East Hants Local Research Ethics Committee.

6.3.1 Advertisement in Local Paper

In Chapter 1.4 we discussed that mass media can only be successful if it:

1. conveys simple information.
2. provides new information, presented in an emotional context.
3. promotes information that is seen as being relevant for “people like me” [26, 128]

When designing the advertisement these three things had to be taken into consideration to ensure the target population was reached. Initially current glaucoma advertisements that have been or are currently published by the IGA and the RNIB were reviewed. Pros and cons were assessed, why these advertisements worked or did not work. Having some idea about what did not work a brainstorming session for ideas on what a glaucoma advertisement should be like followed. Six prototype advertisements were produced and the project’s aims and objectives were discussed and the advertisements viewed at a teaching session where glaucoma doctors, optometrists, orthoptists and nurses were present. Their ideas were gleaned and distilled, recommendations were taken on board and the advertisements were reviewed and redesigned. The next step was to show the examples to glaucoma patients to get feedback and ensure that the ideas and content did not cause anxiety or offend people with glaucoma in any way. From this the advertisements were narrowed down to a choice of three.

These three advertisements were then translated into Hindi. A local community centre in Southall was visited and two focus groups were carried out comprising four or five Hindi-speaking Southall residents aged

45 and above. The focus groups were carried out in Hindi by a colleague, Dr Daksha Patel, who has carried out a number of focus groups in this location before. From these focus groups the advertisement that was thought would have the most impact on our target population in Southall was chosen.

In the Isle of Wight the three advertisements were shown in the local library. Local residents were asked to comment and give feedback on the advertisements. From this session the advertisement that would have the most impact on our target population in the Isle of Wight was chosen. The advertisements were different for each location as it was more important to get the appropriate advertisement for the area rather than put the same advertisement in each location.

At each location participants were asked if they read the local paper and if they listened to the local radio. We also asked our target populations to comment on different logos and suggest which ones could be associated with the advertisement to increase its impact

6.3.2 Interview on Local Radio

It was originally planned to have a radio 'phone-in' on the local radio but, having consulted with the local radio stations and health promotion specialist, Melvyn Hillsdon, it was decided that a 'phone-in' might prove difficult as a one-off slot with limited time. The perceived main disadvantage was that it could result in getting calls not related to the

topic in question. This would take valuable time away from the intended message or we could end up with no calls at all. Sunrise Radio in Southall said they had tried 'phone-ins' in the past, but they had been unsuccessful. Isle of Wight Radio would have been happy for a 'phone-in' but it was important to carry out the same intervention in both locations. It was decided that for the purpose of this study an interview on the radio would be more suitable. The interview was advertised for 3 days prior to it taking place. These advertisements also contained information about glaucoma.

For the radio interview in Southall the advertisements were translated into Hindi and then checked by a Hindi-speaking specialist at the Hospital to ensure they were giving the correct message. A Hindi-speaking glaucoma associate specialist, Mr Kamal Sharma, carried out the interview. The interview took place at 11.00am on Wednesday 10th July: a time when research showed the target population was likely to be listening.

The radio interview on the Isle of Wight was carried out by glaucoma Consultant Mr Ian Murdoch and took place on Thursday 22nd August at 11.30am. Due to the nature of an unstructured interview and the fact that two different people would be interviewed by two different interviewers, the interviews did not follow a set format. They did however cover the same key issues.

6.3.3 Questionnaire

Figure 6.1 shows the questionnaire that was developed to be carried out pre- and post-intervention. The baseline questionnaire was used to establish the proportion of individuals who were positive responders in the absence of a true campaign. The questionnaire was then carried out after the intervention to establish the impact of the campaign.

This questionnaire relates to an eye disease called glaucoma.

Have you heard of glaucoma? YES/NO

If **yes** Was it recently? (where, when)

If **no** Do you know of any eye disease? YES/NO

Have you heard of them recently? (what, where, when)

Do you remember seeing this advert? YES/NO

Did you hear Mr Murdoch talking about glaucoma on Isle of Wight Radio? YES/NO

Age bracket

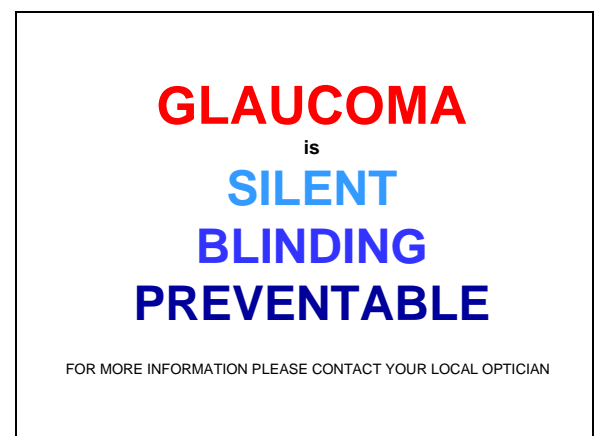
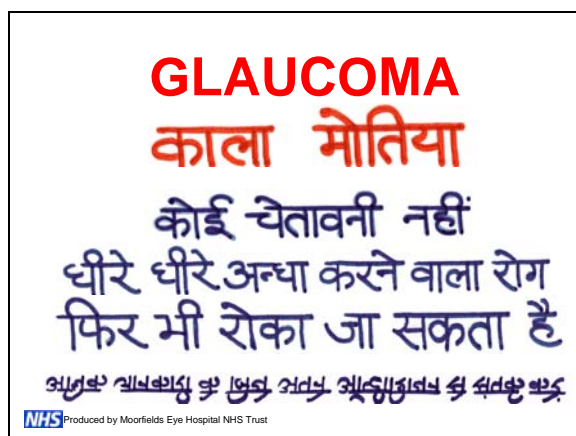
up to 35	36-45	46-55	56-65	66-75	76-85	86+
----------	-------	-------	-------	-------	-------	-----

Occupation

Sex	M : F	Ethnicity	Caucasian : Indian : African : Chinese : Other
------------	-------	------------------	--

Figure 6.1: Baseline & Outcome Questionnaire

6.4 Results of advertisement piloting



(Translation)

Figure 6.2: Advertisement used in Southall Local Paper

The advertisement used in Southall is shown in *figure 6.2*. The advertisement in the Southall local paper had the NHS logo on the bottom of the advertisement. This was used because, in the focus groups, our target population said they thought the NHS logo would add impact to the advertisement as they associated it with free treatment.

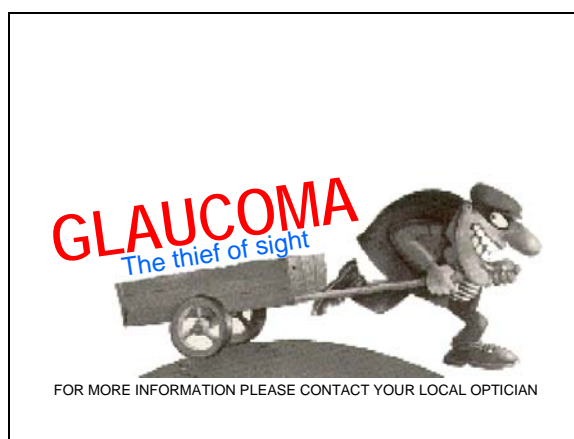


Figure 6.3: Advertisement used in Isle of Wight Local Paper

Figure 6.3 shows the advertisement chosen for the Isle of Wight. The advertisement had no logo or ownership as our target population felt unhappy with the NHS and felt that other logos such as Moorfields Eye Hospital and Thomas Pocklington Trust were not relevant to the Island and would give out the wrong message to our target readers.

MVO: Translated to Hindi Mature deep voice, serious and formal throughout.
MVO: Glaucoma is,..... Silent,.....Blinding,.....Preventable.

For more information listen to Sunita talking to Dr Sharma this Wednesday at 11am

Figure 6.4: Advertisement used on Southall Radio

MVO: *Mature, deep voice, serious and formal throughout.*

MUSIC: *Mysterious music, simple, effective. Not overpowering – just quiet in background*

MVO: There is a thief among us who will steal our most precious belonging...our sight.

Glaucoma affects 1 to 2 percent of the population aged over 40.

It's a disease that attacks the visual field of the eye and if left untreated can cause blindness.

The good news is... cases can be diagnosed by high street optometrists and treated early.

Prevent the preventable...have regular check ups every 2 to 3 years.

Ask your optician or GP for details or visit the Moorfields Eye Hospital website at Moorfields dot org dot uk.

For more details listen to Ian Murdoch, Glaucoma Consultant when he talks to Alex Dyke live on this Thursdays show at 11.30 in the morning.

Figure 6.5: Advertisement used on Isle of Wight Radio

The radio advertisements for Southall and the Isle of Wight are shown in *Figures 6.4 and 6.5*. Both radio advertisements were based on the newspaper advertisement for each area and from the discussions with each target population.

6.5 Results of study

Local residents in Southall all reported reading the local paper and listening to Sunrise Radio. On the Isle of Wight local residents all reported reading the County Press but only 50% reported listening to the local radio.

Summative evaluation has been used to analyse the results, recording the differences between pre- and post-intervention.

6.5.1 Southall

Two hundred and three people were interviewed pre-intervention, of whom 13 were excluded for being too young, leaving 190 interviewees. Three hundred and three people were interviewed post-intervention and five were excluded for being too young leaving 298 people. There was a difference in the numbers collected pre- and post-intervention due to the fact that one of the data collectors did not turn up and there was only one day available to collect the baseline data as the advertisement was going to be in print the next day.

The demographics are shown in *Table 6.1*. It can be seen that a younger group were interviewed prior to the intervention. In addition, a higher proportion of Africans were included in the sample prior to the intervention.

	<i>Pre</i> <i>N =190</i>	<i>Post</i> <i>N=298</i>
<i>Age Group</i>		
46-55	24(13%)	16(5%)
56-65	48(25%)	41(14%)
66-75	74(39%)	146(49%)
76-85	33(17%)	78(26%)
86+	11(6%)	17(6%)
	Chi ² = 22.4 p<0.001	
<i>Gender</i>		
Male	99(52%)	153(51%)
Female	91(48%)	145(49%)
	Chi ² = 0.03 p=0.87	
<i>Ethnicity</i>		
Indian	170(89%)	290(97%)
African	19(10%)	8 (3%)
Other	1 (1%)	0
	Chi ² = 13.5 p<0.001	

Table 6.1: Southall Demographics

The crude differences between pre- and post-intervention groups are shown in *Figure 6.6*. Those who had seen the advertisement rose from 4% to 27%. This is an increase of 23% which is highly significant ($P < 0.001$). Those who had heard the radio advertisement rose from 7% to 20%, an increase of 17% which is also highly significant ($P < 0.001$). Those who had heard of glaucoma increased from 27% to 40% - a rise of 13% which had a p value of $P = 0.003$.

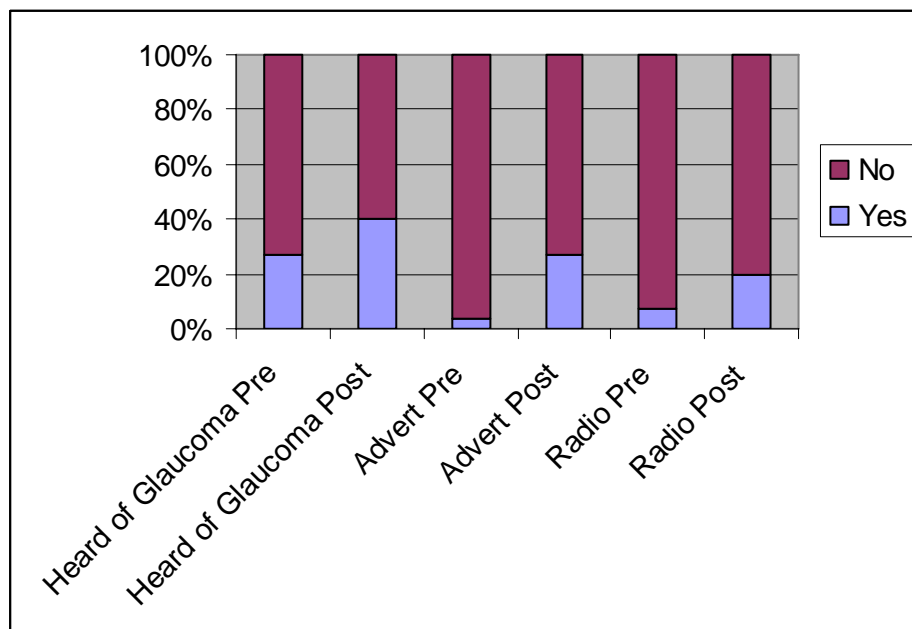


Figure 6.6: Southall Percentage Data Pre- and Post-Advertisement

Because of the age and ethnic differences identified between pre- and post-intervention samples, the results were reviewed in age-specific and ethnicity-specific groups. A consistent effect was seen across all groups indicating true effect with no confounding.

6.5.2 Isle of Wight

Three hundred and five people were interviewed pre-intervention, of whom one was excluded for being too young leaving 304 interviewees.

Three hundred and twelve people were interviewed post-intervention and none were excluded.

Table 6.2 shows the demographics for the Isle of Wight. No substantial difference existed between the pre and post intervention samples in terms of sex, age or ethnicity.

	Pre <i>N</i> =304	Post <i>N</i> =312
Age Group		
46-55	83(27%)	75(24%)
56-65	79(26%)	90(29%)
66-75	89(29%)	99(32%)
76-85	44(14%)	42(13%)
86+	9(3%)	6(2%)
	Chi ² = 2.196 p=0.7	
Gender		
Male	121(40%)	121(39%)
Female	183(60%)	191(61%)
	Chi ² = 0.067 p=0.796	
Ethnicity		
Caucasian	304(100%)	311(99.6%)
African	0	1 (0.4%)
	Chi ² = 0.974 p=0.324	

Table 6.2: Isle of Wight Demographics

Figures 6.7 shows those who had heard of glaucoma rose from 71% to 79% (P=0.025) Those who had seen the advertisement rose from 9% to 18%. This was an increase of 9% which was significant (P<0.001) Those

who had heard the radio advertisement proved not to be significant and increased by only 1%, rising from 2 - 3%.

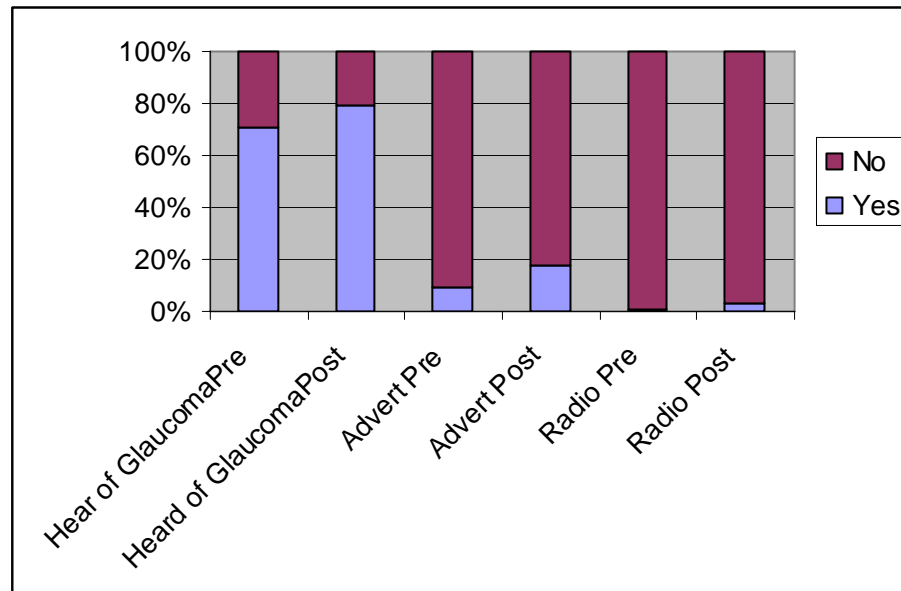


Figure 6.7: Isle of Wight Percentage Data Pre- and Post-Advertisement

6.6 Discussion

In Southall there was a significant impact, with a higher proportion of individuals reporting seeing the advertisement, hearing the interview and having heard of glaucoma after the intervention. On the Isle of Wight the same findings occurred for having seen the advertisement and having heard of glaucoma but there was no effect in terms of those reporting hearing the radio interview.

There were striking differences between the two populations. Not only was the ethnic composition different, as anticipated, but it was also the case that many more people at baseline had heard of glaucoma in the

Isle of Wight (71%) compared to in Southall (27%). Despite this limitation an effect was still demonstrated on the Isle of Wight.

Only Southall showed an effect from the Radio interview, with an increase of 13%. As mentioned earlier, preliminary work in both areas prior to the interview showed that everyone reported listening to Sunrise Radio in Southall whilst only 50% in the Isle of Wight reported listening to local radio. This would allow for a smaller effect of this medium on the Isle of Wight compared with Southall. However, for it to have no effect there must have been other contributing factors. The interview could have been placed at the wrong time of day for our target population although we did try to get around this by having the advertisements leading up to the interview throughout the day. On the day of the interview on the Isle of Wight, glaucoma was also featured as an item in their 6am and 6pm news programmes. This, however, was not mentioned by any of the interviewees. In contrast, the Southall responses indicated that 8% of those who had heard of glaucoma from the Radio had not listened to the actual interview.

The above findings indicate that further research is required to determine the best method of reaching the target population through radio. Other media may need to be considered.

Positive responders in Southall who had heard advertisements or interviews that had not yet taken place varied between 4% and 7%. The

figure on the Isle of Wight was between 2% and 9%, this is in keeping with previous work [129]. If an average of 5% positive responders is subtracted from the results post-intervention, 22% saw the advertisement in Southall and 13% saw the advertisement on the Isle of Wight. In Southall 15% heard the interview whilst only 2-3% heard the interview in the Isle of Wight showing no clear effect.

6.7 Conclusion

In both locations there was a significant effect on those having heard of glaucoma. This could be attributed to both the advertisement and interview in Southall but would appear to be attributable to the newspaper advertisement alone on the Isle of Wight.

The intervention used the media to 'sell' our health message. This is known as social marketing. The message presented on its own, as it was in this study, may have been useful in raising awareness but is unlikely to influence health-seeking behaviour. In order to be successful in changing peoples' behaviour, mass media would need to be used alongside other health promotion methods.

This pilot study has been invaluable for the main study. The results show a positive outcome to our original question and have played a crucial part in the development of a targeted health promotion campaign.

7.0 PUBLIC AWARENESS

7.1 Introduction

It has already been discussed in Chapter 4 how detrimental late glaucoma diagnosis can be. It has been suggested that the phenomenon of late diagnosis could be due, in part, to low public awareness of glaucoma. This view is supported by data from several studies outside the UK [77, 78, 80, 130, 131] which found poor awareness and knowledge of glaucoma.

After studying patients with glaucoma in Chapter 5, it was concluded that there seemed to be a low knowledge of the disease in patients prior to diagnosis. These patients also stressed that they felt there was low knowledge of glaucoma in the UK public. The pilot study described in Chapter 6 neither supported or contradicted these findings as there was a huge difference in those who had heard of glaucoma between the Isle of Wight and Southall. In order to explore this issue further, an in-depth knowledge questionnaire was undertaken in these two locations and a national sample was taken to estimate national glaucoma awareness. To date, public awareness and knowledge of glaucoma in the UK has not been investigated. This study aimed to address this gap.

Objective: to document public awareness and knowledge of glaucoma.

7.2 Methods

Chapter 4, Section 4.4 looked at questionnaire design and the different ways of administering a questionnaire. In this study both telephone and face-to-face interviewing techniques are used.

The study was comprised of two components. In the first component, detailed interviews were performed with 500 individuals on the Isle of Wight (*Figure 7.1*) and 526 individuals in Ealing (*Figure 7.2*). All the interviews on the Isle of Wight and 226 of the 526 interviews in Ealing were done by telephone. Studies in other subject areas including breast & ovarian cancer [132] and sexual behaviour [133] [134] have used this method successfully. In some cases it has been found that a telephone interview is more suitable because the social distance between the interviewer and respondent can encourage greater honesty [135] [136].



Figure 7.1: Isle of Wight

However, it was noted that the telephone interview procedure in Ealing yielded very few respondents from ethnic minorities despite the availability of Hindi-speaking interviewers. In order to access the ethnic minorities in Ealing, 300 face-to-face interviews were performed in individuals' homes and places of worship and were conducted in their normal spoken language (Hindi, Gujarati, or Punjabi).

For the telephone interviews, a sample of landline telephone numbers was supplied by Survey Sampling Incorporated using their Equal Probability of Selection Method (EPSEM). The EPSEM database has been created from OfTel data, using the basic 'building blocks' from which BT and all telephone providers generate telephone numbers. This means that all numbers have an equal probability of selection, and ex-directory and cable telephone numbers are included.

The face-to-face interviewees were identified by the interviewer attending all places of worship in the area and knocking on peoples' doors on streets that had been selected before the interviews took place to ensure the whole area was covered.

All methods used quota sampling and all participants had to be resident within the study area. For the telephone interviews, there was 2.5 refusals for every acceptance compared with 2.3 refusals for every face-to-face interview.

In the light of the findings from the Isle of Wight and Ealing a national telephone survey of 1009 individuals using the same random telephone dialing methods was performed.

In addition to questions to determine Social Class Grading (NSEC) two questions were asked:

1. Have you heard of glaucoma?
2. What do you think glaucoma is? Just tell me in your own words.



Figure 7.2: Southall, Ealing

7.2.1 Questionnaire

The questionnaire was designed in conjunction with British Marketing Research Bureau (BMRB), specialists in the field, and in liaison with researchers with experience in the area of glaucoma health knowledge [77, 85]. Two agencies (BMRB and Ethnic Media Focus) carried out the interviews. Care was taken in the wording of questions to avoid leading questions and in their ordering to avoid questions which could inform

subsequent responses. The questionnaire was piloted and modified in the light of that experience. Interviews carried out in languages other than English used “local” terms for glaucoma where appropriate. The same questionnaire with a standard introduction was used for all interviews excluding the national sample. The questionnaire started with general health questions that included eye specific topics (e.g. medical checks in last 12 months, diseases heard of). Open questions on glaucoma and cataract were then followed by more detailed questions. Glaucoma knowledge was assessed by 14 true/false questions. The national sample was an omnibus survey carried out by the BMRB which was standardised. (See *Appendix A*).

The open responses were “scored”, being awarded +1 for a correct point concerning the disease and –1 for a wrong point concerning the disease. Individuals with a score below 1 were classified as having no knowledge, those with a score of 1 were classified as having minimal knowledge and those with a score greater than 1 as having some knowledge. An example of a correct answer would be “build up of pressure in the eye”, “can lead to blindness”, “can be treated with eye drops”. Incorrect responses include “something to do with your blood”, “to do with poor diet”, “cannot be treated”.

7.2.2 Ethical Approval

This study had ethical approval from Moorfields Eye Hospital Ethical Committee, Isle of Wight, Portsmouth & South East Hampshire Health Authority Ethical Committee and Ealing Ethical Committee.

7.3 Results

A total of 2071 interviews were completed. The demographic and socio-economic characteristics of four samples are shown in *Table 7.1*. There were similar numbers of male and females. The national sample included individuals aged less than 35 years but did not include anyone in the “routine”, “semi-routine” or unemployed groups.

Of the 2071 individuals interviewed, 1531 (74%) reported having heard of glaucoma. The most striking observation with respect to these responses was the major difference in the proportion having heard of glaucoma between the Ealing face-to-face interviews (23%) and the other groups (78% or greater) (*Table 7.1*). Using Chi² analysis, being female ($P=0.001$), age over 34 years ($P=0.02$) and higher social class ($P<0.001$) were all associated with an increased probability of having heard of glaucoma.

		IoW telephone	Ealing telephone	National survey	Ealing Face-to- face	Total
Sex	Male	205/226 (91%)	83/115 (72%)	364/477 (76%)	40/165 (24%)	692/983 (70%)
	Female	260/274 (95%)	123/147(84%)	427/532 (80%)	29/135 (21%)	839/1088 (77%)
Age (yrs)	0-34	-	-	170/258 (66%)	-	170/258 (66%)
	35-44	60/67 (90%)	48/57 (84%)	181/227 (80%)	6/48 (13%)	295/399 (74%)
	45-54	112/114 (98%)	59/78 (76%)	137/158 (87%)	36/94 (38%)	344/444 (77%)
	55-64	131/140 (94%)	33/44 (75%)	130/159 (82%)	17/75 (23%)	311/418 (74%)
	65+	161/178 (90%)	61/78 (78%)	162/193 (84%)	10/83 (12%)	394/532 (74%)
NSECa	Higher professional	46/47 (98%)	17/19 (89%)	174/199 (87%)	7/14 (50%)	244/279 (87%)
	Lower Professional	101/108 (94%)	29/35 (83%)	264/329 (80%)	7/19 (37%)	401/491 (82%)
	Intermediate	58/61 (95%)	19/23 (83%)	148/191 (77%)	10/23 (43%)	235/298 (79%)
	Small employers	21/22 (95%)	1/1 (100%)	79/114 (69%)	8/36 (22%)	109/173 (63%)
	Technical	28/30 (93%)	13/14 (93%)	104/143 (73%)	9/24 (38%)	154/211 (73%)
	Semi-routine	54/61 (89%)	30/40 (75%)	-	10/50 (20%)	94/151 (62%)
	Routine	54/58 (93%)	10/18 (56%)	-	15/98 (15%)	79/174 (45%)
	Unemployed	3/4 (75%)	5/12 (42%)	-	0/20 (0%)	8/36 (22%)

Table 7.1: Distribution by sex, age, area and NSECa for having heard of glaucoma.

The difference between ‘heard of glaucoma’ and ‘heard of other diseases’ can be seen in *Table 7.2*. The figures for glaucoma were taken at the first time of asking rather than after the repeated prompt “can I just check if you have heard of glaucoma?” which is used for all the other tables.

	IoW telephone	Ealing telephone	National survey	Ealing Face-to- face
Glaucoma (On 1 st asking)	465 (96%)	206 (79%)	-	69 (23%)
Cataract	482 (96%)	218 (83%)	-	298 (99%)
Diabetic eye disease	364 (73%)	190 (73%)	-	217 (72%)
Macular degeneration	171 (34%)	87 (33%)	-	21 (7%)
Psoriasis	412 (82%)	177 (68%)	-	84 (28%)
Tinnitus	416 (83%)	163 (62%)	-	103 (34%)
Arthritis	480 (96%)	223 (85%)	-	273 (91%)
Alzheimers	467 (93%)	208 (79%)	-	140 (47%)
Multiple Sclerosis	468 (94%)	213 (81%)	-	70 (23%)

Table 7.2: Numbers who had heard of other diseases

Table 7.2 shows the Ealing face-to-face group to be on the whole less aware of all other diseases. They did however have comparable awareness of cataract, diabetic eye disease and arthritis. The Isle of Wight and Ealing telephone had high awareness of glaucoma, cataract and diabetic eye disease. All groups had low awareness of macular degeneration (34% Isle of Wight, 33% Ealing telephone) with Ealing face-to-face being the lowest at 7%. The table highlights the low awareness of glaucoma in the Ealing face-to-face group.

A logistic regression model was then constructed with 'heard of glaucoma' as the outcome (*Table 7.3*). The results were consistent with those of the crude analysis presented in *Table 7.1*. Eleven regions were sampled in the national sample. The proportion who had heard of glaucoma between regions ranged from 71 - 86% ($\text{Chi}^2=25.8$ $p=0.17$).

Variable		Adjusted odds ratios (95% confidence interval)	P-value
Sex	Female	1.0	0.02
	Male	0.75 (0.58, 0.96)	
Age	<35 years	1.0	<0.0001
	35 - 44	2.10 (1.41, 3.13)	
	45 – 54	4.26 (2.71, 6.70)	
	55 - 64	2.43 (1.59, 3.72)	
	65+	2.30 (1.52, 3.49)	
Source	IoW telephone	1.0	<0.0001
	Ealing telephone	0.25 (0.14, 0.44)	
	National telephone	0.23 (0.14, 0.38)	
	Ealing face-to-face	0.03 (0.02, 0.04)	
NSECA	Higher managerial	1.0	<0.0001
	Lower managerial	0.62 (0.37, 0.98)	
	Intermediate	0.55 (0.34, 0.90)	
	Small employers	0.33 (0.20, 0.56)	
	Lower supervisory	0.40 (0.24, 0.67)	
	Semi-routine	0.24 (0.13, 0.46)	
	Routine	0.18 (0.10, 0.34)	
	Unemployed	0.05 (0.02, 0.14)	

Table 7.3: Odds ratios for the associations between the outcome “having heard of glaucoma” and sex, age, sampling source and NSECa

Respondents' knowledge of glaucoma was assessed in two ways. First, those interviewed were asked how much they considered they knew about glaucoma. Second, an open-ended question was asked: ‘What do you think glaucoma is? Just tell me in your own words’. Not all who had heard of glaucoma responded to this question (1362/1531 (89%)). Of those who responded 86% gave an answer that included some reference to the eye. *Table 7.4* shows the results of these two assessments.

		IOW telephone	Ealing Telephone	Ealing Face- to-face	Whole country *	Total
Own assessment	Knowledge					
	Nil	96 (20%)	3 (1%)	21 (31%)	-	120 (15%)
	Small	145 (30%)	65 (29%)	16 (24%)	-	236 (30%)
	Some	241 (50%)	158 (70%)	30 (45%)	-	429 (55%)
Open question responses	Nil	96 (25%)	50 (32%)	2 (4%)	107 (14%)	255 (18%)
	Small	160 (42%)	64 (41%)	11 (24%)	460 (58%)	695 (50%)
	Some	129 (34%)	44 (28%)	33 (72%)	224 (28%)	430 (31%)

*The nationally representative sample was not asked this self assessment question.
NB: Fewer answered the open-ended question.

Table 7.4: Level of knowledge about glaucoma.

7.4 Discussion

7.4.1 Principal Findings

The first major finding of this study is that more people have heard of glaucoma than had previously been anticipated. However, much lower awareness was found in the face-to-face interviews in the ethnic minority population. One possible explanation for this finding is that the telephone sampling procedure resulted in bias towards a more aware population. While the low response rate (about one third) provides substantial scope for selection bias (since non-response is not a random process), it is not lower than that reported for other telephone surveys [137]. The findings suggest that the difference in awareness of glaucoma between the face-

to-face interviewees and the telephone interviewees does not simply reflect selection bias in the two different recruitment methods but could reflect a real underlying difference.

In addition to a larger proportion having heard of glaucoma than previously thought, over 80% of those who had heard of the disease reported some additional knowledge about it. This profession of knowledge was supported by the proportion of people who demonstrated correct knowledge in response to the open-ended question.

7.4.2 Implications for Health Professionals and Policy Makers

The low level of awareness in the face-to-face interviews in Ealing is important in highlighting a potential deficiency of random telephone interviews. The telephone sampling method found the same level of awareness of glaucoma as the national sample (78%). The face-to-face interviews found 23% awareness. It can be hypothesized that in an area with a high ethnic minority population, such as Ealing, the telephone is more likely to be answered by an English-speaking member of the family who is more informed, or not answered at all. This has important consequences for the interpretation of other studies in which sampling was undertaken by random digit dialing. Pockets of ethnic or other minorities may not be properly represented. This phenomenon has not been previously reported [90] [138].

7.4.3 Limitations

In Ealing it was in the Indian population in which we observed a low awareness of glaucoma. Although face-to-face interviewers used colloquial terms for the word glaucoma for clarity when required, it is possible this reflects issues of translation rather than poor understanding of glaucoma. However we think this is unlikely as in the same questionnaire participants were asked if they had heard of cataract to which 99% of the population answered yes and 72% had heard of diabetic retinopathy.

The areas of low awareness are a concern and, in the case of the ethnic minorities in Ealing, we are addressing this with a public health campaign to see if awareness about glaucoma can be improved. Interestingly, those who were aware of glaucoma in this subgroup had a high degree of knowledge of glaucoma.

7.4.4 Relationship to Other Studies

The higher level of awareness contrasts with findings from other countries [78, 85], and from previous qualitative studies [126] [139]. This observation argues against a lack of awareness being the main reason why only 50% of glaucoma cases have been diagnosed at any one time.

Awareness of glaucoma was slightly higher among females than males (77% vs 71%). This finding is consistent with other studies [85] [82].

Awareness was lower among those aged less than 35 years. The work of Michielutte in 1984 [82] also found younger people to be less knowledgeable.

People from higher social class were more aware although there is a bias in the national sample; no individuals from semi-routine, routine or unemployed were sampled. This is likely to mean we have a slight over estimate of numbers who have heard of glaucoma in the national sample. However the results from the other telephone interviews include these grades and show similar proportions having heard of glaucoma. The Whitehall study [140] found that lower social classes had a higher incidence of disease and discussed aspects such as lifestyle, environmental and occupational exposures, including the psychosocial to consider as factors contributing to this. If we assume that awareness leads to an increased chance of diagnosis then it is more likely for the lower social classes to be undiagnosed in the community going blind from the disease. This is consistent with Fraser et al who have shown that people in lower social classes are more at risk from going blind from glaucoma due to late presentation [141].

7.5 Conclusion

It appears that it would be wrong to assume that people in the UK have not heard of glaucoma. This study has shown that not only have the majority of older people heard of the disease but that they also have a degree of knowledge about the disease. Why then are only 50% of glaucoma sufferers diagnosed and receiving therapies? Our findings suggest that a “culture” of regular optometric visits to check on general eye health is not widespread and that many people only associate optometric visits with the need for glasses. The RNIB have reported lack of awareness to be one of the barriers to eyes tests in older people [142]. In light of our findings, this requires further investigation.

This is the first study of public health knowledge of glaucoma across the UK. This study observed a higher than anticipated level of awareness and knowledge of glaucoma and highlighted a limitation of a telephone survey approach. In this study it is possible that a telephone survey missed a pocket of low awareness.

8.0 PUBLIC HEALTH CAMPAIGN

8.1 Introduction

The results of the previous studies indicated that raising awareness about glaucoma may lead to more patients being diagnosed and receiving treatment. This chapter will look at the main study: a public health campaign to raise awareness about glaucoma and encourage the over 60's in Southall, Ealing, to go and have their eyes tested by their local optometrist. Data were collected in three areas:

1. Levels of knowledge in the target population pre- and post-intervention.
2. Number of people going to their optometrist for an eye test pre- and post-intervention.
3. Number of referrals to the hospital pre- and post-intervention.

Objectives

The specific objectives were:

1. to develop health promotion materials to raise public awareness of glaucoma and the needs of glaucoma sufferers.

2. to make the public aware of the need for routine eye checks and the importance of eye health.
3. to investigate whether a public health promotion campaign can raise awareness of glaucoma as a stand-alone intervention.
4. to assess the impact of a health promotion campaign on help-seeking behaviour

8.2 Methods

8.2.1 Study Location

Southall, Ealing, was the chosen area for our study. The pilot study had shown that the knowledge of glaucoma in the Indian population in Southall, Ealing, was low [143]. Previous work had collected considerable background information on positive predictive values of glaucoma referrals and optometric practice within the area [127]. As a result, there was an excellent working relationship with the optometric community.

In 2001, the Borough of Ealing had a population of 300,948 people of whom 46,865 were over 60 and 49,734 were of Indian origin.

8.2.2 Baseline and Outcome Measures

The health knowledge questionnaire described in Chapter 7.2 was carried out, with 300 interviews taking place pre- and 307 interviews post-intervention. Following verbal consent, the questionnaire started with

general health questions that included eye specific topics (e.g. medical checks in last 12 months, diseases heard of). Open questions on glaucoma and cataract were then followed by more detailed questions. Glaucoma knowledge was assessed by 14 true/false questions. (See *Appendix A*)

Initially, 226 interviews were carried out in Ealing using telephone interviews. (Studies in other fields including breast and ovarian cancer [132] and sexual behaviour [144] have used this method successfully.) In some instances it has been found that a telephone field work method is more suitable due to the social distance between the interviewer and respondent. This can encourage greater honesty. We found this method failed to access the ethnic minorities in Ealing and therefore discontinued it. Instead, face-to-face interviewing was used for this group as it was felt a better response rate would be achieved. Previous research using this method had proved successful [143]. Face-to-face interviews were performed in individuals' homes or places of worship and were conducted in their normal spoken language (Hindi, Gujarat, or Punjabi). This was found to be a more appropriate method of data collection in the Indian population, allowing for greater parity.

8.2.3 Advertising Campaign

The health intervention comprised four components.

1. Advertisements on the television.
2. Advertisements in the local press
3. Advertisements and interviews on local radio
4. Posters displayed in places of worship

The target population was people aged 60 and above who were resident in Southall. The aim of the campaign was to get people to have their eyes tested at their local optometric practice. We had ethical approval for the study from Moorfields Eye Hospital Ethical Committee.

Prior to producing any press materials, focus groups were held within the area of the target population. The aim of these groups was to supplement data collected in the pilot study (Chapter 6) and specifically find out what publications they read, which television stations they watched and which radio stations they listened to. They were also asked where they felt it would be appropriate to advertise the campaign.

8.2.3.1 Role of Advertising Agency McCann Erickson

To produce the best possible media for the campaign within the projects budgetary restraints the advertising agency McCann Erickson were

approached. The advertising agency gave their time and expertise for free and were involved in the creative production of the media. The investigator was involved in the decision process at every stage and had the final say on production and dissemination.

8.2.4 Optometric Data

All optometric practices within the Borough of Ealing were asked to collect data for the study. Practices collected data for 6 months before and after the advertising campaign.

Optometrists were asked to fill in the year of birth of everyone who came for a sight test and to tick next to the year of birth if they subsequently referred them to the hospital for glaucoma. Practices were also asked to fill in the waiting time for a routine appointment at their practice. Forms were filled in and returned in pre-paid envelopes on a weekly basis.

For a period of one month before and after the advertising campaign, four practices asked people coming for eye tests what had motivated them to come .

8.2.4.1 Analysis

All data from the optometric practices and the health knowledge questionnaire pre- and post-intervention was coded and cleaned. Tests of

significance were carried out to assess statistical significance for differences in proportion and logistic regression was undertaken to assess confounding. All statistical analyses were carried out using Stata7 (pub StataCorp 2001).

8.2.5 Positive Predictive Power of Referrals to Ealing Hospital

The positive predictive value (PPV) of optometric referrals has been assessed at Ealing Hospital for the last 10 years. To ensure a reliable and accurate comparison of the number of optometrist referrals and PPV post-intervention to the baseline figures, the methods remained unchanged from the pre-intervention investigation by Patel *et al* [145], and its associated studies [146, 147].

A referral for suspected glaucoma was defined as any concern relating to a single or any combination of findings (including IOP, disc excavation and field defects) that the referring optometrist had attributed to other pathology. Optometrists were unaware that their referrals were being analysed.

Patients excluded from the study included those previously diagnosed with glaucoma, those referred for other conditions and subsequently found to have glaucoma, those whose referrals were not initiated by an optometrist (i.e. direct GP referrals or referrals from other hospital departments) and those who failed to attend their appointment.

All newly referred patients had a structured assessment including history, visual acuity, Goldmann applanation tonometry, slit lamp examination, gonioscopy, optic disc assessment with biomicroscopy through dilated pupils and visual field examination on a Humphrey visual field analyser. They were assessed by any of the team of ophthalmologists and optometrists in the clinic on the day.

The waiting time for patients to be seen in the glaucoma clinic following an optometrist referral for suspected glaucoma was usually less than three months. From September to November only four such optometrist referrals made after the start of the intervention were seen in the clinic. Notes of all new referrals seen in the clinic over the six month period starting December 2007 were therefore collected. All information was recorded on data collection proformas. Relevant details were recorded on a bespoke database. The subsequent database was cross-checked with the new patients listed on the clinical profiles over the same period to ensure maximal data capture.

The notes were prospectively assessed by one glaucoma consultant and only used information recorded at the initial clinic visit, classified as confirmed glaucoma, suspected glaucoma or not glaucoma (glaucoma negative). The term glaucoma includes the diagnoses of open angle glaucoma (OAG), angle closure glaucoma (ACG) and secondary glaucoma. The diagnostic outcomes of all referrals were also recorded.

For the purpose of PPV calculation, a positive outcome was defined by a classification of confirmed or suspected glaucoma. As it was considered entirely appropriate that glaucoma suspects were referred for ophthalmological review, they were included in the positive outcome category.

The targeted Asian community was filtered from the pre- and post-intervention data. Where ethnicity was recorded in the patients notes it was entered onto the database. Where ethnicity had not been recorded it was determined from the patient name by a suitably experienced individual. The accuracy of using surnames and forenames in ascribing Asian ethnic identity has been proven to have high reliability in previous studies [148, 149]. The number of referrals and PPV for this particular ethnic group was then determined pre- and post-intervention.

8.2.5.1 Analysis

The majority of the analysis involved descriptive statistics. These yielded absolute numbers of referrals by source, reasons for referral and data supplied in referrals letters. In addition, the proportion attending and the proportion with positive clinical findings (positive predictive value of referral diagnosis of suspected glaucoma) was determined. Secondary outcomes included the agreement of hospital clinical findings with those in referral letters. Comparative analysis has been undertaken between years to estimate any effect of the public health intervention.

8.3 Advertising Campaign

8.3.1 Introduction

The campaign was run throughout the month of September 2007. The decision was made to run the campaign at this time of year as it was felt that during the summer months the target population were liable to be out of the country on holidays and the football world cup was likely to dominate the early part of summer. The month of September was thought to be ideal as it leads up to Diwali (Indian festival of lights) and the majority of people were expected to be in our targeted area. *Table 8.1* shows a summary of the media used and its output.

Press	▪ One advertisement running in two local papers and in three national Asian publications throughout September
T.V.	▪ Three advertisements running on 5 Asian channels. Each advertisement ran once a day on all channels throughout September ▪ One advertisement running on Channel 4 once a week for four weeks as part of their Hindi Season
Radio	▪ One advertisement running on three Asian radio stations. ▪ Interviews and phone-in carried out on two different radio stations
Temple	▪ Temple poster delivered to 15 places of worship in Southall

Table 8.1: Summary of Media Output.

8.3.2 Press



**YOUR VISION
MAY BE
NARROWER
THAN YOU
REALISE**



**ASK YOUR
LOCAL
OPTICIAN
FOR a FREE
GLAUCOMA
EYE TEST.
IT'S QUICK
SIMPLE, & IF
YOU'RE
OVER 60
FREE**

**MOORFIELDS
EALING
PROJECT**



Guide Dogs

Figure 8.1: Advertisement in English



Figure 8.2: Advertisement in Hindi

English (Figure 8.1) and Hindi (Figure 8.2) advertisements were run on alternate weeks in the Ealing Times and Ealing Leader for four weeks. The Hindi advertisement was run in the September monthly publications of Asian Voice and Gujarat Samachar.

8.3.3 Radio

Radio Advert

Look at the radio you are listening to.

In fact take two steps back from the radio and stare directly at it.

Without moving your eyes, see how much you can see out of the corner of each eye.

Now slowly turn your head two inches in each direction.

Did you miss anything that surprises you?

A loved one sitting in the armchair perhaps, a picture of your beautiful grandchildren on the far wall? Or maybe your Sanskrit scriptures (garanth) lying on the table?

Don't be alarmed, but your vision may be narrower than you thought.

Actually be a little alarmed, because this could be a sign of glaucoma. Glaucoma is an eye condition that gradually narrows your vision.

It creeps up over so many years that most people aren't even aware that it's happening to them.

If you do have glaucoma and you leave it unchecked your vision will narrow further.

If over time you go blind, you will lose sight of everything you hold dear.

Testing for glaucoma is quick, simple, and if you're over sixty years old, free.

Make an appointment with your local optician, and see that glaucoma isn't happening to you.

Figure 8.3: Radio Advertisement

One Radio commercial was produced and translated into Hindi and Punjabi (*Figure 8.3*). It was broadcast on three different Radio stations (Sunrise Radio, Punjab Radio and Desi Radio) every day throughout September between 3 and 5 times a day.

8.3.4 Television

Three advertisements (*Figures 8.4, 8.5 and 8.6*) were produced.

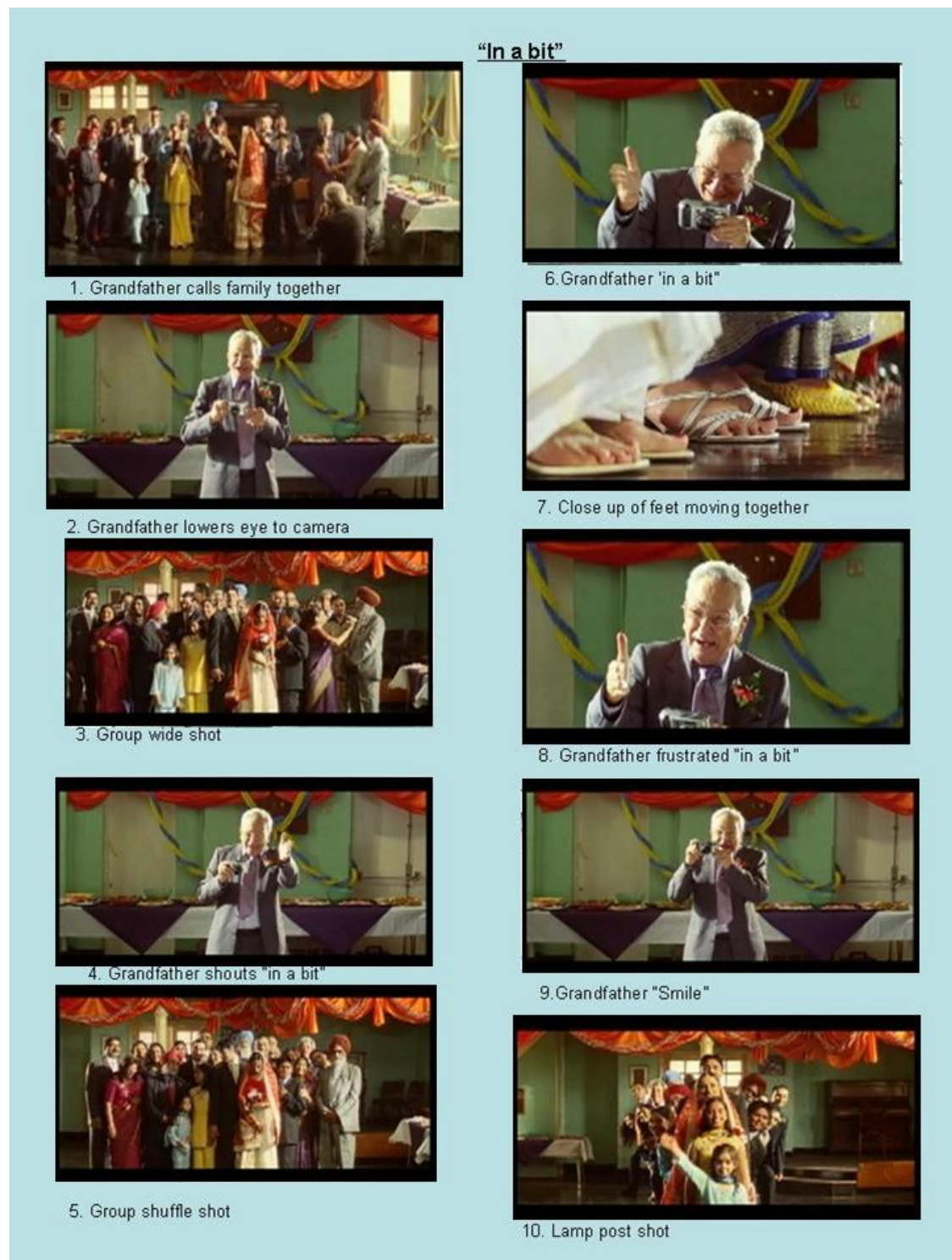


Figure 8.4: Advertisement 1. "In a Bit"

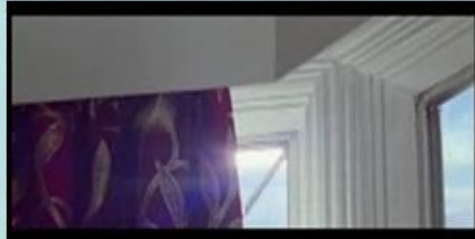
Curtains



1. Grandmother looking out of window



2. Grandmother's view outside



3. Curtains begin to close



4. Looking outside at children, curtains closing



5. Close up on grandmother



6. Shadow from curtains creeps over her



7. Curtains close even further



8. Extreme close up of grandmother's eyes



9. Curtains closed blocking all light



10. Message shot

Figure 8.5: Advertisement 2: Curtains

Hellooo!



1. Children running to meet grandparents



6. Grandparents waiting to see grandchildren



2. Grandfather shouts 'hello' arms wide open



7. Children rush in towards grandparents



3. Children run into grandfather's arms



8. Arms narrow as grandmother only see one grandchild



4. Grandmother saying 'hello' arm wide open



9. Other grandchildren look crestfallen



5. Children run into her arms



10. Messgae shot

Figure 8.6: Advertisement 3: Hellooo!

The advertisements were translated into Hindi and were run on six different Asian television stations (Zee T.V., Bangla T.V., Venus, MATV, Sony ETA, Channel S)

8.3.5 Places of Worship

Figure 8.7 shows the poster designed to be placed on the walls in places of worship in Southall. It is 2.5 meters in length and is designed as a fun way for people to test their field of vision.



Test Your Eyesight Here

Stand in position. Look directly ahead and fix your eyes on either the star or the disc. Without moving your eyes or your head. See if you can see the two red lines spaced nine elephants apart. If you cannot, you may have an eye condition called glaucoma. Ask your local optician for a glaucoma eye test. It's quick, simple and if you are over 60, free.

Figure 8.7: Poster for Places of Worship

The poster was placed in 15 places of worship in Southall. They included mosques, Sikh & Hindu temples, and churches. The place of worship was given the choice of having the poster in either English or Hindi.

8.4 Results and Analysis of Advertising Campaign

8.4.1 National Sample

From the national sample taken in our public health knowledge questionnaire a 1000 people were asked if they had heard of glaucoma. *Table 8.2* shows the results of the national sample along with the results of our other baseline data taken from the Isle of Wight and Ealing (Chapter 7). Highlighted is the percentage of people who had heard of glaucoma in our target population: the face-to-face interviews in Ealing. This shows that a low percentage of people had heard of glaucoma.

Area	N	Heard of glaucoma (%)
Telephone, Isle of Wight	500	465 (93.0%)
Telephone, Ealing	262	206 (78.6%)
Self- completed IoW	88	84 (96%)
London	150	108 (72%)
South East	183	157 (85.8%)
South West	85	66 (78%)
Wales	52	43 (83%)
East Anglia	41	29 (71%)
East Midlands	73	56 (77%)
West Midlands	96	71 (74%)
Yorks/Humber	88	76 (86%)
North West	99	75 (76%)
North	58	46 (79%)
Scotland	83	64 (77%)
Face-to-face, Ealing	300	69 (23.0%)

Table 8.2: Baseline data (including national sample) on number who had heard of glaucoma.

8.4.2 Demographics

Sex	Pre	%	Post	%
Male	165	55	180	59
Female	135	45	127	41

Table 8.3: Sex

The sex of those interviewed is shown in *Table 8.3*. The ages of those interviewed in the pre- and post-intervention data collection periods are shown as percentages in *Figure 8.8*. There was no difference between the two groups (Pearson $\chi^2 = 10.4433$ $P = 0.235$).

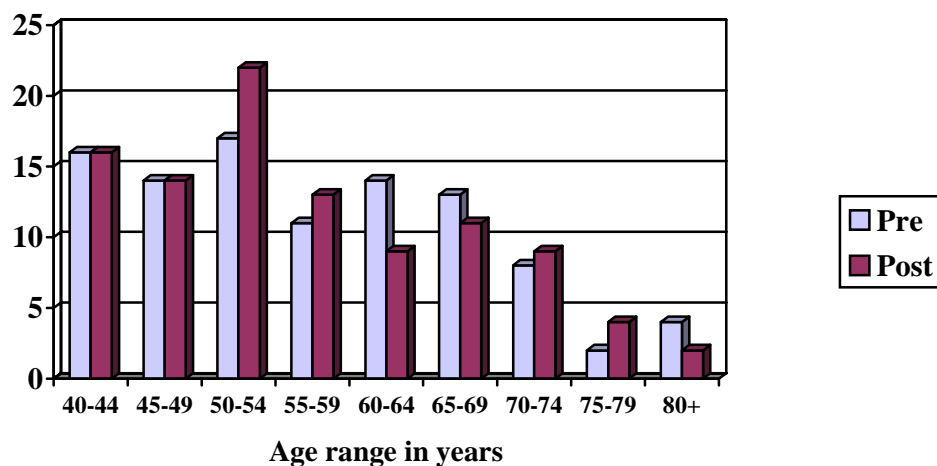


Figure 8.8: Percentage distribution of age group interviewed by pre/post intervention.

Religion	Pre	%	Post	%
Hindu	109	36	49	16
Muslim	47	16	55	18
Seikh	142	47	201	66
Other	2		1	

Table 8.4: Religion

The religion of those interviewed prior to the intervention were equally split (*Table 8.4*). There were proportionately more Sikh's amongst those

interviewed after the intervention. The number of those coded as “other” was 2 pre- intervention and 1 post-intervention.

8.5 Results

8.5.1 Validity

Both glaucoma and cataract respondents who answered that they had never heard of the disease were asked a second time if they were sure. Concordance of responses was 96% for glaucoma and 94% for cataract. The amount of knowledge professed in 7 individuals who only answered positively for having heard of glaucoma on the second asking was very low suggesting validity. Further validity was suggested by the fact that none of the 120 who said they had only heard of the name glaucoma gave a response in the section where they were asked to describe it. This validity was also true for cataract.

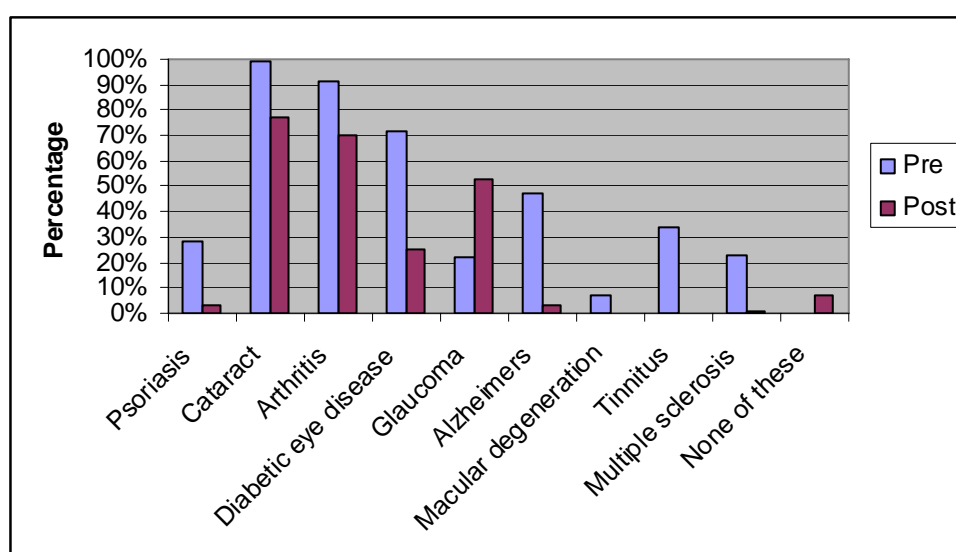


Figure 8.9: The proportion who had heard of different diseases pre/post Intervention.

Figure 8.9 shows the proportion who had heard of different diseases before and after the intervention. You can see that post interview the sample of people were less knowledgeable about all other diseases, making the effect on glaucoma more profound.

The proportion of people who had heard of glaucoma increased from 67 (22%) to 163 (53%) ($\text{Chi}^2 = 61$ $P < 0.001$). By contrast, the proportion who had heard of other eye diseases in interviews after the intervention was lower, emphasising the unique impact on glaucoma (*Table 8.5*).

Disease	Pre-intervention Heard (%)	Post-intervention Heard (%)	Chi ²
Cataract	298 (99%)	236 (77%)	72 $p < 0.001$
Diabetic eye disease	217 (72%)	76 (25%)	
Macular degeneration	21 (7%)	0 (0%)	22 $p < 0.001$
Glaucoma	67 (22%)	163 (53%)	61 $p < 0.001$

Table 8.5: Number who had heard of eye diseases pre- and post-intervention.

In order to assess the effect of the intervention in the context of having heard of other disease conditions the proportion who had heard of glaucoma but not other conditions was examined pre and post intervention. This is shown in *Table 8.6*. This table suggests that the effect of the campaign seems to have been directly on having heard of glaucoma.

		Number (%) who had heard of glaucoma but not the other disease	
Disease		Pre-intervention N=300	Post-intervention N=307
Ocular	Cataract	0 (0%)	8 (3%)
	Diabetic eye disease	3 (1%)	97 (32%)
	Macular degeneration	48 (16%)	163 (53%)
Other	Psoriasis	28 (9%)	158 (51%)
	Tinnitus	30 (10%)	162 (53%)
	Arthritis	2 (1%)	42 (14%)
	Alzheimer's	17 (6%)	154 (50%)

Table 8.6: Number who had heard of glaucoma but not the other diseases.

Heard of glaucoma from:	Pre (%)	Post (%)
Doctor/GP	13 (19%)	10 (6%)
Optometrist/optician	6 (9%)	1 (<1%)
Health professional	0 (0%)	1(<1%)
Friend or relative	24 (36%)	14 (9%)
Friend or relative have disease	12 (18%)	2 (1%)
Leaflet or poster	1 (1%)	0 (0%)
TV	2 (3%)	8 (5%)
Radio	0 (0%)	111 (69%)
Newspaper/magazine	3 (4%)	4 (2%)
Patient	0 (0%)	2 (1%)
Just know	6 (9%)	3 (2%)
GP & radio	0 (0%)	3 (2%)
GP & Newspaper/magazine	0(0%)	1 (<1%)
TV & radio	0(0%)	2 (1%)
Total	67	162

Table 8.7: Where did you hear of glaucoma?

Table 8.7 shows where individuals had heard of glaucoma. Prior to the intervention, those who said they had heard of glaucoma reported having gained an awareness about it from their GP (19%), a friend or relative (36%), or by word of mouth. None reported having heard of glaucoma via the radio. After the campaign, 111 (69%) of those who had heard of glaucoma reported having done so via the radio.

<u>Source</u>	Glaucoma Pre N (%)	Glaucoma Post N (%)
Any advertisement/publicity for glaucoma	23 (33)	119 (72)
Television programme	6 (9)	5 (3)
Television advertisement	0 (0)	9 (5)
Radio programme	0 (0)	3 (2)
Radio advertisement	0 (0)	113 (69)
National newspaper advertisement	0 (0)	2 (1)
Local paper advertisement	0 (0)	1 (1)
Magazine advertisement	0 (0)	1 (1)
Magazine article	12 (17)	0 (0)
Posters at doctors/health setting	2 (3)	5 (3)
Leaflets at doctors/health setting	7 (10)	2 (1)
Posters on billboard	0 (0)	1 (1)
Posters at bus shelter	1 (1)	0 (0)
Web/internet	1 (1)	0 (0)
Don't know where heard	0 (0)	2 (1)
No response	0 (0)	14 (9)
Have seen TV programme	5 (7)	4 (2)
Have seen TV advertisement	0 (0)	2 (1)
Have seen radio programme	4 (6)	0 (0)
Have seen radio advertisement	0 (0)	9 (5)
Have seen national newspaper advertisement	0 (0)	1 (1)
Have seen national newspaper article	1 (1)	2 (1)
Have seen local newspaper advertisement	0 (0)	14 (9)
Have seen local newspaper article	3 (4)	9 (5)
Have seen magazine advertisement	0 (0)	3 (2)
Have seen magazine article	2 (3)	3 (2)
Have seen poster in healthcare setting	2 (3)	8 (5)
Have seen leaflet in healthcare setting	2 (3)	4 (2)
Have seen poster on billboard	0 (0)	3 (2)
Have seen poster on bus	0 (0)	1 (1)
Do not know where they have seen anything	0 (0)	5 (3)
Total asked	69	164

Table 8.8 Have you heard or seen an advertisement for glaucoma?

Table 8.8 shows the large increase in people who had seen an advertisement post-intervention. This rose from 23% to 72%, the majority of whom (69%) had heard a radio advertisement.

Source	Glaucoma Pre N	Glaucoma Post N
BBC Asian net	11 (8)	2 (2)
BBC local	17 (8)	2 (1)
Capital fm	4 (2)	1 (1)
Classic fm	1 (1)	1 (1)
Heart	2 (1)	1 (1)
Kiss 100	1 (0)	0
LBC fm	0	1 (0)
Magic	1 (0)	0
Radio 1	4 (3)	0
Radio 2	1 (1)	0
Radio 4	3 (3)	0
Radio 5 live	2 (1)	0
Sunrise radio	179 (48)	47 (29)
Talk sport	1 (1)	0
Team talk 252	1 (0)	0
XFM	0	1 (1)
Desi radio	138 (28)	146 (98)
Club asia	3 (1)	3 (3)
Punjab radio	68 (14)	58 (34)
Ahash radio	7 (1)	2 (2)
Amritwani	13 (0)	1 (0)
Other specified	39 (7)	1 (0)

Table 8.9: What radio stations do you listen to? Bracketed numbers are the number who had heard of glaucoma.

Source	Glaucoma Pre N	Glaucoma Post N
Sunrise radio	179 (48) 26%	47 (29) 61%
Desi radio	138 (28) 20%	146 (98) 67%
Punjab radio	68 (14) 21%	58 (34) 59%

Table 8.10: Percentage of those who listen to radio station who had heard of glaucoma.

From *Table 8.9* the majority of respondents listen to the three radio stations where we placed advertisements. *Table 8.10* shows the clear increase in the number who listened to these radio stations and had heard of glaucoma after the intervention.

	Pre N (n who had heard of glaucoma)	Post N (n who had heard of glaucoma)
Currently work in health field	5 (3)	1 (1)
Worked in health field in past	13 (7)	3 (2)
Never worked in health field	282 (59)	298 (160)

Table 8.11: Number who had worked in the health field. Bracketed are the number who had head of glaucoma.

From *Table 8.11* we can see that very few participants had worked in the health field. Of those who had, there were more pre- than post-intervention.

	N pre-intervention		N post intervention	
	Not heard of glaucoma	Heard of glaucoma	Not heard of glaucoma	Heard of glaucoma
Worn glasses	179	60	110	146
Worn contact lenses	0	0	2	0
Worn neither	52	8	27	17
Don't know	0	1	0	0

Table 8.12: Number who wear glasses/contact lenses.

If participants wore either glasses or contact lenses they were more likely to have heard of glaucoma. This is shown in *Table 8.12*.

Amount known	Pre N (column %)	Post N (column %)
A lot	0 (0)	1 (0.6)
A little	9 (13)	0 (0)
Hardly anything	21 (31)	9 (6)
Only know name	16 (24)	53 (33)
Don't know	21 (31)	99 (61)
Total	67	162

Table 8.13: How much do you know about the disease?

When asked the question “How much do you know about the disease?”

(Table 8.13), the majority claimed to know very little.

Of those that had heard of glaucoma, about half (109 (48%)) professed any more knowledge than having simply heard of the condition. There were proportionately more professing knowledge prior to the campaign (46/67 (69%)) than in those after the campaign (63/163 (39%)).

After an open-ended question asking what they thought glaucoma was, 15 true/false questions were asked about glaucoma. No clear pattern was shown between groups pre- and post-intervention in terms of knowledge.

Question	Pre N (%) Correct	Pre n (%) Wrong	Post N (%) Correct	Post n (%) Wrong
You usually know if you have glaucoma	22 (49)	2 (4)	45 (71)	5 (8)
There is more than one type of glaucoma	4 (9)	1 (2)	35 (56)	2 (3)
Africans are more likely to have glaucoma	1 (2)	3 (7)	26 (41)	9 (14)
Glaucoma can be inherited	25 (54)	5 (11)	36 (57)	7 (11)
Headaches are commonly associated with glaucoma	1 (2)	25 (54)	7 (11)	37 (59)
High blood pressure can lead to glaucoma	2 (4)	27 (59)	11 (17)	36 (57)
Glaucoma causes loss of peripheral vision	45 (98)	0 (0)	43 (68)	0 (0)
Glaucoma is caused by an infection of the eye	2 (4)	5 (11)	5 (8)	39 (62)
Men are more likely to have glaucoma	4 (9)	8 (17)	5 (8)	36 (57)
Glaucoma can lead to permanent blindness	42 (91)	1 (2)	38 (60)	11 (17)
Glaucoma may be caused by high IOP	45 (98)	0 (0)	32 (51)	12 (19)
Glaucoma affects the optic nerve at the back of the eye	18 (39)	0 (0)	31 (49)	11 (17)
Glaucoma causes a film of skin to grow over the inside of the eye	0 (0)	11 (24)	11 (17)	29 (46)
Generally don't get glaucoma until older than 40 years	12 (26)	6 (13)	28 (60)	10 (16)
Treatment for glaucoma	17 (37)	13 (28)	2 (3)	53 (84)

Table 8.14: Detailed questions about glaucoma. (Purple shows an increase, blue stayed the same and pink shows a decrease).

Table 8.14 shows the results of questions asked to ascertain detailed knowledge. We can see that detailed knowledge did not improve post-intervention. However, the absolute numbers getting it right did not really change, thus implying core knowledge in both groups.

8.5.2 Specific Responders

The data was then explored to see if a specific group responded to the campaign.

Age group (yrs)	Pre N (% total in age group)	Post N (% total in age group)
40-44	6 (13)	26 (53)
45-49	18 (42)	25 (58)
50-54	18 (36)	39 (59)
55-59	4 (12)	24 (60)
60-64	13 (30)	13 (45)
65-69	6 (15)	13 (39)
70-74	4 (16)	17 (61)
75-79	0 (0)	6 (46)
80+	0 (0)	1 (20)

Table 8.15: Number who had heard of glaucoma split by age.

We can see from *Table 8.15* that the effect was clear in all age groups.

	Males N (% total males)	Females N (% total females)
Pre-intervention	40 (24)	29 (21)
Post-intervention	93 (52)	71 (56)

Table 8.16: Number who had heard of glaucoma split by sex.

Religion	Pre N (% total in group)	Post N (% total in group)
Hindu	32 (29)	32 (65)
Muslim	14 (30)	28 (51)
Seikh	22 (15)	104 (52)

Table 8.17: Number who had heard of glaucoma split by religion.

Tables 8.16 and 8.17 show that there was no difference between the sexes and that the campaign had had a clear effect across all religious groups.

Check	Pre N (%)	Post N (%)	Chi ²
Dental	162 (54)	201 (66)	8.61 (p=0.003)
Cholesterol	150 (50)	220 (72)	30.5 (p=0.000)
BP	238 (79)	265 (87)	5.67 (p=0.017)
Eye test	193 (64)	239 (78)	14.0 (p=0.000)
None of above	38 (13)	18 (6)	8.3 (p=0.004)

Table 8.18: Number of reported tests in the last 12 months

We can see from Table 8.18 that there was an increase in the proportion of people who had had check-ups for a number of health-related issues. We then looked to see if those who have regular health checks are more likely to have responded.

	Proportions who had heard of glaucoma			
	In those who had test		In those who did not have test	
Test in last year	Pre N (%)	Post N (%)	Pre N (%)	Post N (%)
Dental	40 (25)	123 (61)	29 (21)	41 (39) (6.67 P=0.01)
Eye test	47 (24)	143 (60)	22 (21)	21 (31) (11.7 P=0.001)
BP	53 (22)	150 (57)	16 (26)	14 (34) (9.25 P= 0.002)
Cholesterol	42 (28)	131 (60)	27 (18)	33 (38) (9.14 P=0.003)

Table 8.19: Proportions who had heard of glaucoma who did or did not have health checks.

Table 8.19 shows that there was an effect in those who had checks and those that did not. The effect was bigger in the group that had had recent checks.

Time of last eye test	Pre N (%)	Post N (%)
Test in last year	47 (71)	143 (87)
Less than 2 years ago	7 (11)	2 (1)
2-5 years	11 (17)	14 (9)
Over 5 years ago	1 (2)	4 (2)
Don't know	0 (0)	1 (1)
Total	66	164
(Chi ² 8.33 P=0.004)		

Table 8.20: Number of people who had heard of glaucoma who had been for an eye test.

From *Table 8.20* we can see that more individuals reported having had an eye test in the last year after the campaign. There is a suggestion that the knowledge of glaucoma in part accounted for this increase since the higher number who had heard of glaucoma also seem to have attended for a recent eye test. These results are shown in *Table 8.21*. A Chi² test was used pre-intervention and again post-intervention. It was only significant post-intervention, where a higher proportion of those who had heard of glaucoma had had a recent eye test.

	Pre-intervention Chi ² 0.7 p=0.4		Post-intervention Chi ² 15.2 p <0.001	
	Not heard	Heard	Not heard	Heard
No recent eye test	86 (37%)	21 (31%)	45 (31%)	21 (13%)
Recent eye test	147 (63%)	46 (69%)	99 (69%)	142 (87%)
	233	67	144	163

Table 8.21: Proportion who had heard of glaucoma and reported recent eye test pre- and post-intervention.

8.5.3 Logistic Regression

Explanatory variable for knowledge of glaucoma	Crude OR	Adjusted OR*
Pre/post intervention	3.94 (2.77-5.60) ‡	6.41 (4.11-10.0) ‡
Increasing age (5 year bands)	0.91 (0.85-0.99) ‡	0.89 (0.80-0.99) ‡
Sex	0.99 (0.71-1.38)	1.35 (0.87-2.09)
Having an eye test in the last year	2.38 (1.60-3.54) ‡	1.99 (1.21-3.26) ‡
Educational qualification	0.70 (0.60-0.81) ‡	0.68 (0.56-0.83) ‡
Social class (NS SECA)	0.79 (0.72-0.87) ‡	0.85 (0.76-0.95) ‡
Having a cholesterol check in last year	2.65 (1.85-3.80) ‡	
Having a BP check in last year	1.79 (1.12-2.86) ‡	
Having a dental check in the last year	2.00 (1.41-2.83) ‡	
Religion	0.93 (0.77-1.12)	
Having heard of cataract	5.78 (2.72-12.3) ‡	12.9 (5.36-30.9) ‡
Having heard of arthritis	1.03 (0.68-1.56)	
Having heard of diabetic eye disease	1.71 (1.23-2.38) ‡	
Having heard of psoriasis	1.55 (0.99-2.41)	
Having heard of alzheimers	1.07 (0.73-1.56)	
Having heard of macular degeneration	16.9 (3.39-73.2) ‡	
Having heard of tinnitus	0.95 (0.61-1.47)	
Having heard of multiple sclerosis	3.03 (1.83-5.02) ‡	

*Adjusted for pre/post intervention, age, sex, and having an eye test in last year

‡ = significant at p<0.05

Table 8.22: Crude odds of numerous variables for the outcome of having heard of glaucoma.

Logistic regression was undertaken for the outcome of those who had heard of glaucoma (*Table 8.22*). The crude odds showed significant explanatory variables to be: pre/post intervention; having an eye test in the last year; having other health checks in the last year (dental, BP, cholesterol); and having heard of other ocular conditions (cataract, diabetic eye disease, macular degeneration). There was no association between having heard of glaucoma and having heard of most other systemic diseases. Younger people were more likely to have heard of

glaucoma. Similarly, being in a higher social class meant you were more likely to have heard of glaucoma as did having a higher educational qualification. The data was examined for co-linearity between the level of educational qualification and social class. This was not found to be a factor. A more complex model was constructed to look for confounding factors, including the variables age, sex, having an eye test in the last year, educational qualification, social class, and having heard of cataract. It can be seen that the effect of the intervention and knowledge of another eye disease was increased with correction of confounding. The other effects were not substantially changed.

8.6 Results and Analysis of Optometric Data

8.6.1 Analysis of optometrist appointment and referral data

The maximum number of weeks for which data were recorded was 26. There were 26 practices in the Borough of Ealing of whom 20 participated. The twenty practices participated in data collection in 2004, contributing a range of 1-26 weeks of data with an average of 14.5 weeks. Eleven practices of the 20 participated in data collection in 2007 contributing a range of 1-24 weeks of data with an average of 13.5 weeks. Four practices had closed in the intervening period (one for refitting and one that did not respond in 2004). No new practices had opened in the area.

There was no major change in the average number of appointments per practice per week between 2004 and 2007 (32 vs 31). This was true if restricted to those aged 40 years and over (19 vs 20) and those aged 60 years and over (12 vs 11).

For the eleven practices with paired data from 2004 and 2007 there were changes in both directions of increased and decreased appointments.

This was related to staff and opening time changes as outlined in *Table 8.23*

Average appointments per week	2004	2007	Comments
Boots Optician	129	46.6	Reduction from 4 optometrists in 2004 to 2 optometrists in 2007
David Clulow Opticians	35.5	31.3	Same staff
Greenford Medical Eye Centre	4.94	5.0	Same staff
Hynes Optometrists	64.1	77.0	Same Staff
J Wexler	3.32	3.9	Same Staff
Keena Rakkado	11.2	8.0	Same Staff
Kenneth H Kennell	25.7	19.0	Same Staff
Mirage Opticians	27.8	32.1	Same Staff
Robert J Lynch	23.8	26.0	Same Staff
Ultimate Eyecare	40.8	39.9	Same staff
Vision Eyecare	9.4	29.0	Open more days

Table 8.23: Average appointments per week for eleven practices with data collected in 2004 and 2007.

Some modelling was undertaken to estimate the total number of sight tests over the 26 week collection period in 2004 and again in 2007. For those practices with data, the average number of patients seen per week (over whatever data collection period applied) was multiplied by 26. For those practices with no data, the average number seen per week for

those who had given data over the period was multiplied by 26. The totals thus generated are shown in *Table 8.24*.

	All appointments	Appointments for those aged 40 and over	Appointments for those aged 60 and over
2004	21635	13179	8193
2007	17669	11230	6220

Table 8.24: Estimated number of sight tests over 26 week collection periods in both 2004 and 2007 for all optometric practices in the Borough of Ealing.

It can be seen that, if anything, there is a reduction in the number of optometrist sight tests following the health intervention. The estimation methods and data available, however, are not robust for tight confidence intervals around these estimates and the only real conclusion is that no major change was observed.

The optometrists also recorded those who were referred to the hospital for suspected glaucoma. The numbers here are small and hence the confidence intervals around any estimates even wider. A similar modelling to that for the appointments was carried out to estimate the total number of referrals for suspected glaucoma in the Borough of Ealing during the 26 week period of data collection in 2004 and 2007. The results are shown in *Table 8.25*.

	All appointments	Appointments for those aged 40 and over	Appointments for those aged 60 and over
2004	295	279	186
2007	233	231	112

Table 8.25: Estimated number of cases referred to hospital for suspected glaucoma over 26 week collection periods in 2004 and 2007 for all optometric practices in the Borough of Ealing.

Again, if anything, there was a decrease rather than an increase in referrals. The percentage of total appointments that were referred for glaucoma was the same in each year (295/21635= 1.36% in 2004 and 233/17669= 1.32% in 2007).

8.6.2 Why people go for eye tests

Optometrists at four practices asked people who came for eye tests what had motivated them to come.

		Pre Total (%)	Pre 40+ (%)	Post Total (%)	Post 40+ (%)
1	Routine*	655 (39)	403 (37)	767 (51)	472 (46)
2	Visual changes	262 (16)	190 (17)	197 (13)	184 (18)
3	Visual discomfort	318 (19)	227 (21)	250 (17)	191 (19)
4	Glasses	171 (10)	94 (9)	113 (7)	72 (1)
5	Recommendation (GP, friend, hospital)	69 (4)	58 (5)	36 (2)	28 (3)
6	Glaucoma	51 (3)	50 (5)	41 (3)	40 (4)
7	School/parent	55 (3)	0 (0)	33 (2)	0 (0)
8	Cataracts	27 (2)	27 (2)	15 (1)	15 (1)
9	AMD	6 (>1)	5 (>1)	4 (>1)	4 (>1)
10	Free test	1 (>1)	1 (>1)	6 (>1)	2 (>1)
11	Headaches	19 (1)	8 (1)	29 (2)	10 (1)
12	No test for a while	17 (1)	14 (1)	2 (>1)	1 (>1)
13	Work related	18 (1)	8 (1)	3 (>1)	0 (0)
14	Family history	2 (>1)	0 (>1)	2 (>1)	0 (0)
15	Eye health	3 (>1)	2 (>1)	2 (>1)	0 (0)
16	Miscellaneous	4 (>1)	0 (>1)	7 (>1)	3 (>1)
Totals		1678	1087	1507	1022

*Routine – Pre/Post total $\chi^2 = 45.2$ $P=0.001$ Pre/Post 40+ total $\chi^2 = 18.0$ $P=0.001$

Table 8.26: Reasons why people go for eye tests.

We can see from *Table 8.26* that there was a significant increase in the number of people coming for a routine appointment post intervention. In

most cases a routine appointment implied they had been sent a reminder letter from the practice.

8.7 Results of Positive Predictive Value

	Pre-Intervention				Post-Intervention			
	No. Referrals	No. Positive Outcome	PPV (%)	95% CI	No. Referrals	No. Positive Outcome	PPV (%)	95% CI
Total referrals	181	78	43	36-50	200	61	31	24-37
Asian referrals	49	22	45	31-59	58	22	38	25-50
Asians 60 years and over	16	10	63	39-86	22	15	68	49-88

Table 8.27: Positive Predictive values pre- and post-intervention.

Six month data was collected from December to May inclusive in 2006 and 2007. 381 referrals for suspect glaucoma were assessed. 181 pre-Intervention and 200 post intervention (*Table 8.27*). The same definition was used for an appropriate referral as in previous reports, namely a diagnosis of confirmed or suspected glaucoma [145, 146]. In the pre-intervention group 78/181 of all assessed referrals resulted in a positive outcome (PPV = 43 (CI 36-50)). After the intervention no real change was demonstrated in the number of referrals or the positive predictive value. The slight decrease in the post-intervention group 61/200 (PPV = 31 (24-37)) was well within chance variation.

The health intervention was aimed at the purely Asian sub-group and it is possible that there was a preferential increase in this population. The names of all referrals were scrutinized and all Asian names identified as

described in chapter 8.2.5 . There was however, no significant change shown, only a slight decrease as above. This decrease is much smaller when looking at the Asian referrals alone with the number of positive referrals being 22/49 (PPV = 45 (CI 31-59)) pre and 22/58 (PPV = 38 (CI 25-50)) post. If the specific target population of Asians aged 60+ is examined then there is an increase in the number of positive referrals 10/16 (PPV = 63 (CI 39-86)) pre and 15/22 (PPV = 68 (CI 19-88)) post. This signifies that despite a slight decrease in the overall PPV there was a slight increase in the target population of Asians over the age of 60. This increase could be due to chance variation or could be the impact of the intervention.

8.8 Discussion

8.8.1 Principal Findings

The pilot study provided a sound understanding of how to reach the target population. Using an interview on local radio and an advertisement in the local paper showed that there was a significant impact using the two media with a higher proportion of individuals reporting seeing the advertisement, hearing the interview and having heard of glaucoma after the intervention in Southall. On the Isle of Wight the same findings occurred for the response to having heard of glaucoma, but there was no effect in terms of those reporting hearing the radio interview. The two populations in this study were strikingly different, but the Isle of Wight

results indicated that reliance should not be placed on these two forms of media alone when planning the main study.

The results of the national sample and the telephone interviews in Ealing and on the Isle of Wight showed a much higher level of public awareness than previously suspected [126, 139]. Although the telephone sampling method was previously reported as valid [132] work prior to this study had suggested a low level of knowledge in the Asian population [143]. After changing to face-to-face interviews, a very different level of knowledge was found to exist. This highlights the importance of choosing the correct data collection method for the target population. It also highlights the limitations of the national sample survey which will have missed an unknown number of similar communities throughout the UK with lower knowledge. This is important since it would be these communities that are most likely to benefit from a public health campaign.

The repeat health knowledge questionnaire showed a striking effect from the campaign. The proportion who had heard of glaucoma more than doubled from 22% to 53%. It is interesting to note that although television advertisements were used that were bright, colourful and frequently aired, it was the radio advertisement that had the most impact. Similarly, advertisements in community settings and local papers had a much smaller effect. The radio was an important form of communication for the target group, as it was created *by* their community *for* their community. This research has shown it is a good way to reach the target population.

This finding shows the importance of learning about your target population. The radio reached 69% of the people who had heard of glaucoma post-intervention.

The findings show that it is not always the most expensive methods that are the most effective. A radio advertisement is relatively cheap to produce and air, yet we have shown that, in the right community, it can have a large effect. Before charities invest in media production, it is important that they look at who they want to reach and how they are going to do it. Time and money spent learning about your target populations' lifestyle habits before materials are created will go a long way to making a campaign successful.

The increased awareness of glaucoma following the campaign was most marked in those who also reported a recent health check for any disease. This suggests a more health-conscious group that has tests and checks, is more responsive to health campaigns. Age and sex made no difference.

The link between having heard of other eye conditions and having heard of glaucoma is less surprising, merely suggesting a more health-aware sub-population. Interestingly, it was the younger age bands that were more likely to have heard of the disease.

Although the proportion who had heard of glaucoma rose strikingly

following the campaign, the degree of knowledge about glaucoma did not really improve. This is not too surprising since the campaign was only designed to improve awareness of the condition. It does however suggest that improved awareness does not lead to spontaneous self education.

The data from optometrist visits for sight tests proved extremely difficult to collect in Ealing. Encouragement had been gained by the remarkable response from the optometrists on the Isle of Wight, who achieved superb data collection for the project. This was not mirrored by the optometrist population in Ealing who achieved very patchy data collection. This resulted in extremely crude estimates of numbers and effect. The results suggest a decline in the number of eye tests from 2004 to 2007. This is most likely due to the second estimate being poorer than the first since many fewer practices participated in the data collection the second time and often for a reduced period of time. It does, however, make the likelihood of a significant impact of the campaign in translating improved awareness to practical action (going for a sight test) unlikely.

In contrast to this finding, the questionnaire after the campaign had more people reporting a sight test in the last year. This might suggest some small prompt to action as a result of the campaign, particularly as a higher proportion of those reporting having gone for an eye test in the last year had heard of glaucoma. Again the confidence intervals around these estimates are large.

This finding could also be supported by the information on why people go for sight tests. The increase in the number of people going for routine eye checks could indicate that the campaign encouraged a positive response to reminders. Further research would be needed to validate this finding.

Changing peoples' behaviour is known to be a difficult task. Chapter 1 shows that making health-related decisions is a complex process and unless a person is ready to take the requisite action, it is unlikely to be effective. Evaluating a health promotion intervention designed to change behaviour would appear to be a simple exercise but as shown with smoking in Chapter 1, Section 1.6.2.1 it is not so easy. To create effect advertising needs to be intense and prolonged. The aim in this case was to assess if the number of eye tests had increased after intervention. The problem with this endeavour is that change may only become apparent over a long period and therefore it may be difficult to isolate any change as being attributable to the health intervention.

Raising awareness and motivating people to action are two separate health promotion issues. It is often assumed that if people are aware of a problem then they will act upon the information. This is often not the case. In this study it was surprising to learn that 74% of people interviewed in the health knowledge questionnaire had heard of glaucoma (Chapter 7) and yet it is still estimated that 50% of glaucoma is undiagnosed [69]. The health campaign more than doubled the number of people aware of glaucoma but this did not have an impact on people going for sight tests.

Previous work carried out in this community [127] had shown health to be a low priority in this group. It could be argued that it is harder to motivate behavioural change in such a group than in people who are already accessing healthcare. The intervention tried to be sensitive to and emotive for the target group, but it failed to trigger behavioural change. One of the reasons could be due to how the optometric practices are perceived in the local community. If optometrists are just seen as a commercial body whose only interest is to make money out of spectacles and not as eye health professionals then this could be a large barrier stopping people having their eyes tested. At present this is just conjecture and more research would be required to analyse the perception of optometric practice in the community.

The campaign had good media coverage but could have lacked enabling factors such as which optometrist to go to, what to expect when they get there. The aim was to keep the message simple and action points clear. The message could have been too simplistic and not specific enough to make the target group think the message was directed towards them. Including the temples and places of worship, plus having interviews and phone-ins on the radio were deliberately chosen to attempt to reach the target population at levels other than just media advertising. Additional devices, such as a stand on the high street giving out information and acting as a point of contact could have been used in this area to have a more direct, personalised approach to encourage action.

8.8.2 Relationship to Other Studies

In the UK, the Department of Health runs a number of large campaigns to improve public health [150]. Sexual health, substance and alcohol abuse, obesity and smoking are some of the areas targeted. These campaigns work together with legislation and the government to raise awareness and motivate change within the nation. Even with this backing, it has proven hard to influence change. It is impossible for the Department of Health to cover every health issue and in many areas it falls to charities and health professionals to try and raise awareness and motivate behavioural change in their specialised areas. Many such campaigns remain un-assessed, unpublished or published internally. Areas where campaigns have been published include physical activity [151], diabetes [152, 153] and sexual health [154]. Our campaign is similar to the diabetic and physical activity campaigns in that it was able to raise awareness but failed to have any significant influence on changing behaviour. Our study's strengths lay in its tight target population.

8.8.3 Strengths and Limitations

This is the first study to assess the impact of an eye campaign in detail. The main limitations of this assessment are the cultural- and area-specific nature of the campaign. The results are therefore only replicable to other

similar communities. Further research would need to be undertaken to assess its impact in different communities.

The collection of data from community optometrists was superb on the Isle of Wight but extremely patchy in Ealing, showing striking regional variation. This was a major limitation to the interpretation of any effect in terms of health-seeking behaviour as a result of the public health campaign. Our contrasting results suggested in the results from the questionnaire (a higher proportion of people who had heard of glaucoma after the campaign reporting having been for an eye test in the last year) highlights this limitation.

8.8.4 Implications for Health Professionals and Policy Makers

Lessons were learned in the undertaking of this campaign. Inside community knowledge proved invaluable in gaining the trust and support of local community groups. Messages can be easily misinterpreted and sensitivities need to be acknowledged. In some temples the poster was refused, and this reluctance to be involved with the campaign was overcome in other places of worship by taking along a colleague of the same religion. Attempts to gain funding from local businesses proved unsuccessful. This could be due to health being a low priority area in this group [127]. Funding was eventually raised through larger international bodies.

Cost is a major issue in any advertising campaign and these findings show that it is not always the most expensive method that can be the most effective. The radio is an important form of communication for our target group, it is made by their community for their community and our research has shown it is a good way to reach this population. As with smoking in Chapter 1, Section 1.6.2.1 a public awareness campaign with a small budget that is supported by local activities can be effective. This finding emphasises the importance of learning about your target population. A radio advertisement is relatively cheap to produce and air but we have shown in the right community it can have a large effect. The radio reached 69% of the people who had heard of glaucoma post intervention.

8.9 Conclusion

This study has shown a major impact on awareness in our target population, particularly through the medium of radio. Before charities put money into media production it is important that they identify who they want to reach and how they are going to achieve this.

9.0 UNIFYING SUMMARY

9.1 Introduction

In this chapter I will look at the findings of the studies in the context of the introduction and previous literature in Chapters 1 to 4. Chapter 1 looked at models of health and gave a broad rationale to health promotion. In order to raise awareness and engage individuals, groups and communities to promote health, these theories and models have been developed as a guide to enable health messages to be effectively communicated and acted upon. When actively working in health promotion it would be unusual for a study to fit into one specific model and, as is the case with these studies, they are more likely to use elements from a broad range of models. The underlying motivation behind all these studies is to prevent people going blind from glaucoma. This has been facilitated by studies which give a better understanding of patient diagnosis, which reveal what it is like to live with glaucoma and which raise awareness about the disease in the general population.

9.1.1 Summary of Research

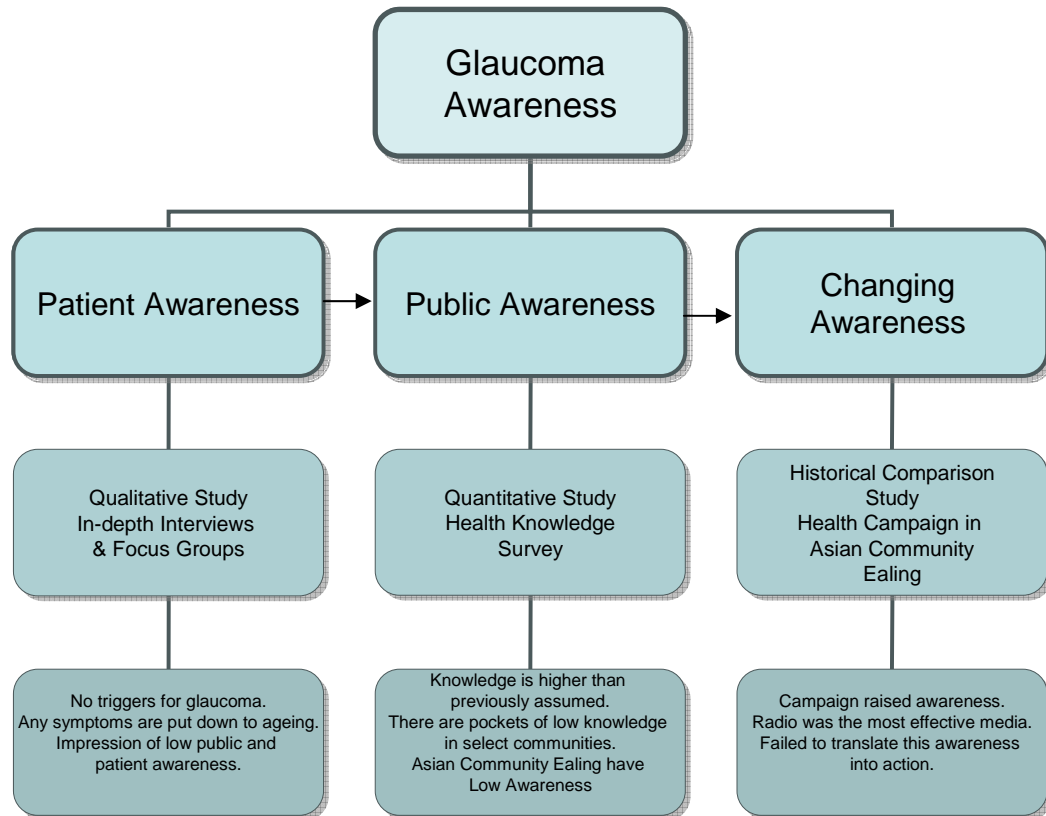


Figure 9.1: Summary of Research

9.2 Summary of Background Literature

9.2.1 Health

The background literature covered the first three chapters of this thesis. Chapter 1 looked at the different models of health. These models can be broken down into two types. Firstly: ideological models, which are theories about people's perceptions and values of health. They include the education model, preventive model and the empowerment model. Secondly: technical models which are theories on how people make their health related decisions. They include the health belief model (HBM), the theory of reasoned action and the health action model (HAM). These models aim to facilitate predictions about the likelihood of individuals or, more problematically, groups of individuals adopting and sustaining a particular course of action.

Health education can take place in many settings and in many forms. This thesis pays special attention to the use of mass media in health promotion. Early theory considered mass media to exert a direct effect on the mass population at which they are targeted. This theory was challenged by Mendelsohn [23] who replaced the image of a hypodermic with that of a aerosol. Some media communication will hit its target, some will drift away and very little will penetrate. The media influence is complex and it will not easily change peoples' behaviour unless the individual's behaviour and influences are favourable to the change. Mass

media alone has a limited capacity. Mass media using 'media advocacy' can be extremely effective in consciousness-raising. Media advocacy focus on changing the way a problem is understood as a public health issue. It works at breaking down the major barriers to health by educating the public, swaying public opinion and influencing policy makers.

Areas where health campaigns have used mass media include obesity, coronary heart disease and smoking. Cochrane has done reviews of interventions for prevention of coronary heart disease and childhood obesity interventions but neither really looks into the mass media aspect. The subject with most published data is smoking.

9.2.2 Visual Impairment

Visual impairment was reviewed in chapter 2. WHO gives us the first worldwidel estimates since the early 1990's estimating that globally, in 2002, more than 161 million people were visually impaired, of whom 124 million people had low vision and 37 million were blind (excluding refractive error)[35]. Except for the most developed countries, cataract remains the leading cause of blindness in all regions of the world. Second is glaucoma, with age-related macular degeneration (AMD) ranking third on the global scale. However, in developed countries, AMD is the leading cause of blindness, due to the growing number of people over 70 years of age.

Nigel Charles for the RNIB looked at the numbers of people visually impaired in the UK. In 2003 there were 370,561 people registered as sight-impaired or severely sight-impaired in England, Wales and Scotland about 68% of whom were over 75 years of age [36]. The RNIB estimates that as many as two out of three people who are eligible to be registered as blind or partially sighted are not registered and those suffering visual impairment could be as many as 1,066,740 [39]. The causes for this impairment were looked at by Tate et al [43] in the prevalence report. This report cites cataract, refractive error and age related macular degeneration as the major causes of visual impairment in the elderly. Although glaucoma and diabetic retinopathy make minor contributions to visual impairment, not all the studies included additional tests such as fields, or funduscopy examination. It is therefore possible that the contribution of glaucoma and diabetic retinopathy to visual impairment may have been underestimated.

9.2.3 Glaucoma

Chapter 3 focused on glaucoma. Quigley estimates that open and closed angle glaucoma affects some 67 million people worldwide [49] and that over 8.4 million people will be bilaterally blind from primary glaucoma in 2010, rising to 11.1 million by 2020.

Primary open-angle glaucoma is a bilateral, usually asymmetric, progressive condition, which is characterized by an open, normal-looking drainage angle and a glaucomatous optic nerve head appearance in the absence of other causative pathology. Due to its slow progression, individuals do not notice any problems in the early stages of the disease. In developed countries only half of all glaucoma sufferers are diagnosed and receiving treatment at any given time [155] [156].

Guide Dogs for the Blind (GDBA) produced a document on the cost of blindness within this they look at the cost of glaucoma [66] The annual total costs associated with this condition ranged from £16 billion to £38 billion. Their reference case estimate was £27 billion. A delay in the onset of significant visual loss has implications not only for patients but also for government expenditures.

Rosenstock's study [4] on health behaviour and health belief suggests that a patient's knowledge concerning the value of regular eye care may play a significant role in seeking eye care. With only 50% of the glaucoma diagnosed in western populations [69, 70] it has been questioned whether it is lack of awareness and knowledge about the disease that could be the root cause [61] .

Table 3.3 showed the various studies that have looked at glaucoma knowledge in different countries. Some studies look at different eye diseases, including glaucoma, and some look specifically at glaucoma. All studies have highlighted a need for health education to be improved.

They also indicate a need for increased knowledge about eye disease and glaucoma independent of the level of awareness in their study. There is an underlying assumption that the more aware and knowledgeable the population is, the more motivated they will be to access eye services and reduce preventable blindness in their populations. The largest difference in awareness and knowledge is between the developed and the developing countries. Within populations the main differences in knowledge are in age and sex. There is a clear lack of UK data in either a clinic-based or population-based form.

9.3 Patient Awareness

Chapter 5 on patient awareness was the first study to look at patients' perceptions and attitudes to living with glaucoma using a qualitative methodology. This study explored the patients' perceptions of their own disease and the effect glaucoma had had on their lifestyle. In Chapter 1, Section 1.3 we looked at the health belief model (HBM), the theory for reasoned action, the health action model (HAM), together with the belief system and the motivation system. All these models try to determine what motivates people into action and what experiences can alter this decision making process. This study investigated these themes as it was important to find out what had prompted patients who had been diagnosed with glaucoma to go for their initial examination. Were there specific symptoms or triggers? What was the impact of these symptoms on everyday life?

Many of the patients were oblivious to their disease until the point of diagnosis, making it difficult to pinpoint any recognisable motivation to action. In many cases, diagnosis was the result of chance rather than a specific symptom prompting the patient to undergo an ophthalmic examination. The HAM and the belief system discussed in Chapter1, Section 1.4.2.3 highlighted two groups of individuals:

1. 'Copers' – individuals who see themselves in charge of their lives and have the capacity to act logically and decisively.
2. People who believe in fate or life being governed by a higher being.

Our participants fall into the category of 'copers'. Their agreement to participate in the study demonstrated their desire to be active decision makers in their eye health. Our patients, with hindsight, definitely regretted not being diagnosed earlier and having more control over their sight loss. The realisation that the sight loss from glaucoma is permanent and that it is vital that the disease is caught in the early stages made all the participants champions of health education. It would be interesting to compare this group to a group of people who believe in fate or that life is governed by a higher being. Would this group be so motivated to raise awareness about the disease? A qualitative study has been undertaken with patients attending an eye clinic in Ghana [157]. This population has a strong belief in fate and of God being in charge of their destiny. Despite this, a sub-group still accessed eye care even if it tended to be seen as a last resort.

9.4 Public Awareness

Chapter 7 looked at public awareness. This was the first study to assess glaucoma awareness and knowledge in the UK. From the findings in Chapter 3, Section 3.3 we can see that our results are similar to those in Australia , New Zealand and Germany. In-depth knowledge is more difficult to compare due to the variety of methods and questionnaire length each study used. In most studies, including our study, the in-depth knowledge was considerably less. Having heard of glaucoma did not necessarily mean that participants were knowledgeable. Interestingly, the poor levels of awareness and knowledge in the Indian community in this study replicates the findings of studies carried out in the developing world. The majority of Indians in my study were first generation immigrants speaking Hindi, so not surprisingly they reflected the attributes of people in their country of origin. The knowledge studies in Chapter 3, Section 3.3 all concluded that there was a need for health education in order to raise awareness about eye disease, leading to an assumption that education will lead to action. From the models discussed in Chapter 1 we know there needs to be a motivational factor. The data from this study was used to provide a baseline to assess if raising awareness through a publicity campaign is enough to create behavioural change with regard to glaucoma.

9.5 Media Campaign

Chapter 1, Section 1.4 looked at health promotion and specifically the use of mass media in health promotion. It has already been stated that it is accepted that mass media, including media advocacy, can raise consciousness about health issues and change behaviour if other enabling factors are present. The health campaign in Chapter 9 aimed to reach these targets. Naidoo and Wills [26] are cited in Chapter 1, Section 1.4 suggesting that mass media including media advocacy can:

- *raise consciousness about health issues*
- *help place health on the public agenda*
- *convey simple information*
- *change behaviour if other enabling factors are present*

Using media is more effective if:

- *it is part of an integrated campaign including other elements such as one-to-one advice*
- *the information is new and presented in an emotional context*
- *the information is seen as being relevant for “people like me”.*

The aim has been to present information in an emotional context by learning about our target population. Meetings were held with target groups and subjects that were important to them were discussed. A high priority to them was family (children and grandchildren) and thus the study aimed to make this a recurrent theme throughout the media. All advertisements were sensitive to age and ethnicity and themed towards the target population. This was done to encourage people to see the information as being relevant for “people like me”. The campaign was run using different types of media in channels that the target population stated they accessed. An outlet was also provided, through which the information received could be used. Phone-ins and interviews on the radio offered pathways to acquire more information and television and other media promoted the optician as the point of call for more information.

Chapter 1, Section 1.4 also highlights the need for pre-testing. The pilot study in Chapter 8 gave a better understanding of the target population and allowed pre-testing of a newspaper and radio advertisement to gauge their effectiveness. This information, together with further discussions with target groups, was invaluable to the structure of the main campaign. All media was pre-tested with the target population, patients and health professionals to ensure accuracy, acceptability and to avoid the possibility of causing offence.

One of the main objectives of the media campaign was to change help seeking behaviour by encouraging the target population to go and have an eye test. From the results of the optometric data in chapter 8.4 the conclusion showed no major change in the numbers attending for eye tests. Why was this the case?

1. The study could have been underpowered but the results do not even show a hint of true change. The only suggestion of change was the self-reported number of people going for an eye test.
2. Chapter 1 highlights that making health-related decisions is a complex process and, unless a person is ready to take action health messages are unlikely to be effective.
3. There could have been spread effect either spatially such as people going outside of Ealing to have an eye test, or temporally which is therefore not showing as significant in our data. The temporal effect could have been a delayed effect which was outside the data collection period or a mild effect over a long period of time.

10.0 FUTURE RECOMMENDATIONS

Although this study has shown a large increase in awareness it has not proven that this is translated into action, i.e. going to an optometrist for an eye check. Further work is needed on this topic which will be challenging to undertake in the light of our experience with optometric data collection.

Looking at what motivates people to have their eyes tested and what the attitudes and perceptions are of the optometric practices would provide invaluable research and offer much needed information to facilitate any further intervention campaigns.

Radio proved to be the most effective medium through which to reach our target population. It would be interesting to see if this is the case in other groups where there is low awareness. It is also important to share these findings with other organizations specialising in vision which invest in media and advertising to raise awareness. When funding and resources are limited it is vital that appropriate media is used and impacts are optimally evaluated.

ABBREVIATIONS

ACG	Angle-Closure Glaucoma
ACT UP	AIDS Coalition to Unleash Power
AIDS	Acquired Immune Deficiency Syndrome
BMRB	British Market Research Bureau
BP	Blood Pressure
DVLA	Driver and Vehicle Licensing Agency
EPSEM	Equal Probability of Selection Method
GDBA	Guide Dogs for the Blind Association
GP	General Practitioner
HAM	Health Action Model
HBM	Health Belief Model
IGA	International Glaucoma Association
IoW	Isle of Wight
MRC	Medical Research Council
MVO	Male Voice Over
NHS	National Health Service
NSEC	National Socio Economic Classification
NSECa	National Socio Economic Classification Abridged
OR	Odds Ratio
POAG	Primary Open-Angle Glaucoma
PPV	Positive Predictive Value
RCO	Royal College of Ophthalmologists
RNIB	Royal National Institute for the Blind

T.V.	Television
UK	United Kingdom
WHO	World Health Organisation

BIBLIOGRAPHY

- [1] World-Health-Organization. Constitution. Geneva 1946.
- [2] Ewles L, Simnett I. Promoting Health: A Practical Guide to Health Education. London: Scutari Press 1992.
- [3] Tones K, Tilford S. Health Promotion: Effectiveness, Efficiency and Equity. 3rd Edition ed: Nelson Thornes 2001.
- [4] Rosenstock I. Why people use health services. Milbank Mem Fund. 1966;44:94-124.
- [5] Janz NK, Becker MH. The Health Belief Model: a decade later. Health education quarterly. 1984 Spring;11(1):1-47.
- [6] Ajzen I, Fishbien M. Understanding Attitudes and Predicting Social Behaviour. Englewood Cliffs, N.J. : Prentice- Hall 1980.
- [7] Baric L. Health education and the smoking habit. Health Educ J. 1978;37:132-7.
- [8] Freidson E. patients views of medical practice. New York: Russell Sage 1961.
- [9] Rotter JB. Generalized expectancies for internal versus external control of reinforcement. Psychological monographs. 1966;80(1):1-28.
- [10] Fishbien M, Ajzen I. Belief attitude, intention and behaviour: an introduction to theory and research. Reading, MA: Addison-Wesley 1985.
- [11] Tones K. Reveille for Radicals! The paramount purpose of health education? Health education research. 2002 Feb;17(1):1-5.
- [12] Freire P. Education and the practice of freedom. London: Writers and Readers Publishing Cooperative 1974.
- [13] World-Health-Organization. Ottawa Charter for Health Promotion, An International Conference on Health Promotion; 1986 November 17-21.
- [14] Chapman S, Lupton D. The fight for public health: principles and practice of media advocacy. London: BMJ 1994.
- [15] Chapman S. Unravelling gossamer with boxing gloves: problems in explaining the decline in smoking. Bmj. 1993 Aug 14;307(6901):429-32.
- [16] Wildson D. The lead scandal. The fight to save children from damage by lead i petrol. London: Heinemann 1983.
- [17] Allain A. IBFAN on the cutting edge. Oslo: Dag Hammarskjold Foundation 1991.
- [18] Wachter R. AIDS, activism, and the politics of health. N Engl J Med. 1992;326(2):128-33.
- [19] Rogers EE, Shoemaker FF. Communication of Innovations. New York: Free Press 1971.
- [20] Cantril H. The Invasion from Mars. In: Maccoby EE, Newcomb TM, Hartley EL, eds. *Readings in Social Psycology*. New York: Henry Holt 1958:291-300.
- [21] Welles O. The War of the Worlds: CBS Radio; 1938.
- [22] Wells H. The War of the Worlds: William Heinemann 1898.
- [23] Mendelsohn H. Which shall it be: mass education or mass persuasion for health? American journal of public health and the nation's health. 1968 Jan;58(1):131-7.

- [24] Wallach LM. Media Advocacy: promoting health through mass communication. In: Glanz K, Lewis FM, Rimer BK, eds. *Health Behaviour and Health Education: Theory, Research and Practice*. San Francisco: Jossey-Bass 1990.
- [25] Tones K. Marketing and the mass media: theory and myth. *Health education research*. 1994 Jun;9(2):165-9.
- [26] Naidoo J, Wills J. *Health Promotion: Foundations for Practice*. 2nd Edition ed: Baillière Tindall 2000.
- [27] Ebrahim S, Beswick A, Burke M, Davey Smith G. Multiple risk factor interventions for primary prevention of coronary heart disease. *Cochrane database of systematic reviews* (Online). 2006(4):CD001561.
- [28] Summerbell CD, Waters E, Edmunds LD, Kelly S, Brown T, Campbell KJ. Interventions for preventing obesity in children. *Cochrane database of systematic reviews* (Online). 2005(3):CD001871.
- [29] The-Department-of-Health. *Smoking kills: a white paper on tobacco.*: HMSO 1998.
- [30] Sutton SR, Hallett R. Experimental evaluation of the BBC TV series "So You Want To Stop Smoking?" *Addictive behaviors*. 1987;12(4):363-6.
- [31] McVey D, Stapleton J. Can anti-smoking television advertising affect smoking behaviour? controlled trial of the Health Education Authority for England's anti-smoking TV campaign. *Tobacco control*. 2000 Sep;9(3):273-82.
- [32] Owen L, Youdan B. 22 years on: the impact and relevance of the UK No Smoking Day. *Tobacco control*. 2006 Feb;15(1):19-25.
- [33] Bala M, Strzeszynski L, Cahill K. Mass media interventions for smoking cessation in adults. *Cochrane database of systematic reviews* (Online). 2008(1):CD004704.
- [34] World-Health-Organization. *International statistical classification of diseases, injuries and causes of death - tenth revision*. Switzerland: WHO; 1993.
- [35] World-Health-Organization. *Magnitude and causes of visual impairment*. 2004 [cited; <http://www.who.int/mediacentre/factsheets/fs282/en/>]. Available from:
- [36] Charles N. Estimates of the number of older people with a visual impairment in the UK. *The British Journal of Visual Impairment*. 2007;25(3):199-215.
- [37] Evans JR, Fletcher AE, Wormald RP. Causes of visual impairment in people aged 75 years and older in Britain: an add-on study to the MRC Trial of Assessment and Management of Older People in the Community. *Br J Ophthalmol*. 2004 Mar;88(3):365-70.
- [38] van der Pols JC, Bates CJ, McGraw PV, Thompson JR, Reacher M, Prentice A, et al. Visual acuity measurements in a national sample of British elderly people. *Br J Ophthalmol*. 2000 Feb;84(2):165-70.
- [39] RNIB. 2001 [cited; <http://www.rnib.org.uk/wesupply/fctsheets/authuk.htm>]. Available from:
- [40] Bunce C, Evans J, Fraser S, Wormald R. BD8 certification of visually impaired people. *Br J Ophthalmol*. 1998 Jan;82(1):72-6.

- [41] Robinson R, Deutsch J, Jones HS, Youngson-Reilly S, Hamlin DM, Dhurjon L, et al. Unrecognised and unregistered visual impairment. *Br J Ophthalmol*. 1994 Oct;78(10):736-40.
- [42] Bunce C, Wormald R. Leading causes of certification for blindness and partial sight in England & Wales. *BMC public health*. 2006;6:58.
- [43] Tate R, Smeeth L, Evans J, Fletcher AE, Owen C, Rudnicka A. The prevalence of visual impairment in the UK: A review of the literature. 2005 [cited; http://www.rnib.co.uk/xpedio/groups/public/documents/publicwebsite/public_c_prevalencereport.doc]. Available from:
- [44] Reidy A, Minassian DC, Vafidis G, Joseph J, Farrow S, Wu J, et al. Prevalence of serious eye disease and visual impairment in a north London population: population based, cross sectional study. *Bmj*. 1998 May 30;316(7145):1643-6.
- [45] Wormald RP, Wright LA, Courtney P, Beaumont B, Haines AP. Visual problems in the elderly population and implications for services. *Bmj*. 1992 May 9;304(6836):1226-9.
- [46] Das BN, Thompson JR, Patel R, Rosenthal AR. The prevalence of eye disease in Leicester: a comparison of adults of Asian and European descent. *Journal of the Royal Society of Medicine*. 1994 Apr;87(4):219-22.
- [47] Gibson JM, Rosenthal AR, Lavery J. A study of the prevalence of eye disease in the elderly in an English community. *Transactions of the ophthalmological societies of the United Kingdom*. 1985;104 (Pt 2):196-203.
- [48] Weinreb RN, Khaw PT. Primary open-angle glaucoma. *Lancet*. 2004 May 22;363(9422):1711-20.
- [49] Quigley HA. Number of people with glaucoma worldwide. *Br J Ophthalmol*. 1996 May;80(5):389-93.
- [50] Thylefors B, Negrel AD. The global impact of glaucoma. *Bull World Health Organ*. 1994;72(3):323-6.
- [51] Thylefors B, Negrel AD, Pararajasegaram R. Epidemiologic aspects of global blindness prevention. *Curr Opin Ophthalmol*. 1992 Dec;3(6):824-34.
- [52] Quigley HA, Broman AT. The number of people with glaucoma worldwide in 2010 and 2020. *Br J Ophthalmol*. 2006 Mar;90(3):262-7.
- [53] Quigley HA, Vitale S. Models of open-angle glaucoma prevalence and incidence in the United States. *Invest Ophthalmol Vis Sci*. 1997 Jan;38(1):83-91.
- [54] Rudnicka AR, Mt-Isa S, Owen CG, Cook DG, Ashby D. Variations in primary open-angle glaucoma prevalence by age, gender, and race: a Bayesian meta-analysis. *Invest Ophthalmol Vis Sci*. 2006 Oct;47(10):4254-61.
- [55] Bathija R, Gupta N, Zangwill L, Weinreb RN. Changing definition of glaucoma. *J Glaucoma*. 1998 Jun;7(3):165-9.
- [56] Foster PJ, Buhrmann R, Quigley HA, Johnson GJ. The definition and classification of glaucoma in prevalence surveys. *Br J Ophthalmol*. 2002 Feb;86(2):238-42.
- [57] Wolfs RC, Borger PH, Ramrattan RS, Klaver CC, Hulsman CA, Hofman A, et al. Changing views on open-angle glaucoma: definitions

- and prevalences--The Rotterdam Study. *Invest Ophthalmol Vis Sci*. 2000 Oct;41(11):3309-21.
- [58] Jay JL, Murdoch JR. The rate of visual field loss in untreated primary open angle glaucoma. *Br J Ophthalmol*. 1993 Mar;77(3):176-8.
- [59] Bell RW, O'Brien C. The diagnostic outcome of new glaucoma referrals. *Ophthalmic Physiol Opt*. 1997 Jan;17(1):3-6.
- [60] Bell RW, O'Brien C. Accuracy of referral to a glaucoma clinic. *Ophthalmic Physiol Opt*. 1997 Jan;17(1):7-11.
- [61] Grant WM, Burke JF, Jr. Why do some people go blind from glaucoma? *Ophthalmology*. 1982 Sep;89(9):991-8.
- [62] Vogel R, Crick RP, Newson RB, Shipley M, Blackmore H, Bulpitt CJ. Association between intraocular pressure and loss of visual field in chronic simple glaucoma. *Br J Ophthalmol*. 1990 Jan;74(1):3-6.
- [63] Heijl A, Leske MC, Bengtsson B, Hyman L, Bengtsson B, Hussein M. Reduction of intraocular pressure and glaucoma progression: results from the Early Manifest Glaucoma Trial. *Archives of ophthalmology*. 2002 Oct;120(10):1268-79.
- [64] Tuck MW, Crick RP. The cost-effectiveness of various modes of screening for primary open angle glaucoma. *Ophthalmic Epidemiol*. 1997 Mar;4(1):3-17.
- [65] Gottlieb LK, Schwartz B, Pauker SG. Glaucoma screening. A cost-effectiveness analysis. *Surv Ophthalmol*. 1983 Nov-Dec;28(3):206-26.
- [66] GDBA. The Costs of Blindness: An analysis of the costs of visual impairment and blindness in the United Kingdom. 2003.
- [67] Royal-College-of-Ophthalmologists. A National Research Strategy for Ophthalmology; 2002.
- [68] Javitt JC. Preventing blindness in Americans: the need for eye health education. *Surv Ophthalmol*. 1995 Jul-Aug;40(1):41-4.
- [69] Coffey M, Reidy A, Wormald R, Xian WX, Wright L, Courtney P. Prevalence of glaucoma in the west of Ireland. *Br J Ophthalmol*. 1993 Jan;77(1):17-21.
- [70] Mitchell P, Smith W, Attebo K, Healey PR. Prevalence of open-angle glaucoma in Australia. The Blue Mountains Eye Study. *Ophthalmology*. 1996 Oct;103(10):1661-9.
- [71] Cross V, Shah P, Bativala R, Spurgeon P. ReGAE 2: glaucoma awareness and the primary eye-care service: some perceptions among African Caribbeans in Birmingham UK. *Eye*. 2007 Jul;21(7):912-20.
- [72] Ellish NJ, Royak-Schaler R, Passmore SR, Higginbotham EJ. Knowledge, attitudes, and beliefs about dilated eye examinations among African-Americans. *Invest Ophthalmol Vis Sci*. 2007 May;48(5):1989-94.
- [73] Costa VP, Spaeth GL, Smith M, Uddoh C, Vasconcellos JP, Kara-Jose N. Patient education in glaucoma: what do patients know about glaucoma? *Arquivos brasileiros de oftalmologia*. 2006 Nov-Dec;69(6):923-7.
- [74] Juzych MS, Randhawa S, Shukairy A, Kaushal P, Gupta A, Shalauta N. Functional health literacy in patients with glaucoma in urban settings. *Archives of ophthalmology*. 2008 May;126(5):718-24.
- [75] Dandona R, Dandona L, John RK, McCarty CA, Rao GN. Awareness of eye diseases in an urban population in southern India. *Bull World Health Organ*. 2001;79(2):96-102.

- [76] Krishnaiah S, Kovai V, Srinivas M, Shamanna BR, Rao GN, Thomas R. Awareness of glaucoma in the rural population of Southern India. *Indian journal of ophthalmology*. 2005 Sep;53(3):205-8.
- [77] Attebo K, Mitchell P, Cumming R, Smith W. Knowledge and beliefs about common eye diseases. *Aust N Z J Ophthalmol*. 1997 Nov;25(4):283-7.
- [78] Lau JT, Lee V, Fan D, Lau M, Michon J. Knowledge about cataract, glaucoma, and age related macular degeneration in the Hong Kong Chinese population. *Br J Ophthalmol*. 2002 Oct;86(10):1080-4.
- [79] Hoevenaars JG, Schouten JS, van den Borne B, Beckers HJ, Webers CA. Knowledge base and preferred methods of obtaining knowledge of glaucoma patients. *Eur J Ophthalmol*. 2005 Jan-Feb;15(1):32-40.
- [80] Pfeiffer N, Kriegelstein GK, Wellek S. Knowledge about glaucoma in the unselected population: a German survey. *J Glaucoma*. 2002 Oct;11(5):458-63.
- [81] Mansouri K, Orgul S, Meier-Gibbons F, Mermoud A. Awareness about glaucoma and related eye health attitudes in Switzerland: a survey of the general public. *Ophthalmologica Journal international d'ophtalmologie International journal of ophthalmology*. 2006;220(2):101-8.
- [82] Michielutte R, Discker RA, Stafford CL, Carr P. Knowledge of diabetes and glaucoma in a rural North Carolina community. *J Community Health*. 1984 Summer;9(4):269-84.
- [83] Gasch AT, Wang P, Pasquale LR. Determinants of glaucoma awareness in a general eye clinic. *Ophthalmology*. 2000 Feb;107(2):303-8.
- [84] Landers JA, Goldberg I, Graham SL. Factors affecting awareness and knowledge of glaucoma among patients presenting to an urban emergency department. *Clinical & experimental ophthalmology*. 2002 Apr;30(2):104-9.
- [85] Livingston PM, Lee SE, De Paola C, Carson CA, Guest CS, Taylor HR. Knowledge of glaucoma, and its relationship to self-care practices, in a population sample. *Aust N Z J Ophthalmol*. 1995 Feb;23(1):37-41.
- [86] Balo PK, Serouis G, Banla M, Agla K, Djagnikpo PA, Gue KB. [Knowledge, attitudes and practices regarding glaucoma in the urban and suburban population of Lome (Togo)]. *Sante (Montrouge, France)*. 2004 Jul-Sep;14(3):187-91.
- [87] Danesh-Meyer HV, Deva NC, Slight C, Tan YW, Tarr K, Carroll SC, et al. What do people with glaucoma know about their condition? A comparative cross-sectional incidence and prevalence survey. *Clinical & experimental ophthalmology*. 2008 Jan-Feb;36(1):13-8.
- [88] Noertjojo K, Maberley D, Bassett K, Courtright P. Awareness of eye diseases and risk factors: identifying needs for health education and promotion in Canada. *Canadian journal of ophthalmology*. 2006 Oct;41(5):617-23.
- [89] Paczka JA, Ochoa-Tabares JC, Giorgi-Sandoval LA, Topete-Jimenez J, Sanchez-Castellanos VE, Jauregui-Garcia DG, et al. [Knowledge and perceptions of glaucoma among adults living in an urban area]. *Gaceta medica de Mexico*. 2006 Jul-Aug;142(4):303-8.

- [90] Newman W. Survey Research. *Social Research Methods: Qualitative and Quantitative Approaches*. 5th ed: Allyn and Bacon 2003:289-90.
- [91] Mays N, Pope C. Qualitative research: Observational methods in health care settings. *Bmj*. 1995 Jul 15;311(6998):182-4.
- [92] Mays N, Pope C. Rigour and qualitative research. *Bmj*. 1995 Jul 8;311(6997):109-12.
- [93] Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *Bmj*. 2000 Jan 1;320(7226):50-2.
- [94] Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *Bmj*. 1995 Jul 1;311(6996):42-5.
- [95] Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *Bmj*. 2000 Jan 8;320(7227):114-6.
- [96] Patton MQ. *Qualitative Research & Evaluation Methods* 3rd ed: Sage Publications, Inc 2002.
- [97] Whyte WF. Interviewing in field research. In: Burgess RG, ed. *Field research a source book and field manual*. London: George Allen and Unwin 1982:111-22.
- [98] Field PA, Morse JM. *Nursing research: the application of qualitative approaches*. London: Chapman & Hall 1989.
- [99] Glaser B, Strauss A. *The Discovery of Grounded Theory*. London: Weidenfield & Nicolson 1967.
- [100] Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: B.A.B.R., ed. *Analysing Qualitative Data*. London: Routledge 1994.
- [101] Ritchie J. Qualitative data analysis for applied policy research. In: B.A.B.R., ed. *Analysing Qualitative Data*. London: Routledge 1994.
- [102] Green J, Browne J. *Principles of Social Research*: Open University Press 2006.
- [103] Parrish RK, 2nd. Visual impairment, visual functioning, and quality of life assessments in patients with glaucoma. *Trans Am Ophthalmol Soc*. 1996;94:919-1028.
- [104] Owen J, Herse P. Low vision and surfing. *Optom Vis Sci*. 1996 Aug;73(8):558-61.
- [105] Fagerstrom R. Correlation between depression and vision in aged patients before and after cataract operations. *Psychological reports*. 1994 Aug;75(1 Pt 1):115-25.
- [106] Shmueli-Dulitzki Y, Rovner BW. Screening for depression in older persons with low vision. Somatic eye symptoms and the Geriatric Depression Scale. *Am J Geriatr Psychiatry*. 1997 Summer;5(3):216-20.
- [107] Lane SD, Mikhail BI, Reizian A, Courtright P, Marx R, Dawson CR. Sociocultural aspects of blindness in an Egyptian delta hamlet: visual impairment vs. visual disability. *Medical anthropology*. 1993 Aug;15(3):245-60.
- [108] Armstrong D, Weinman J, Marteau T. The place of inter-rater reliability in qualitative research: an empirical study. *Sociology*. 1997;31:597-606.
- [109] Epstein DL. *Chandler and Grant's Glaucoma*. Third Edition ed: Lea & Febiger 1986.

- [110] Hitchings RA. Glaucoma: BMJ Publishing Group 2000.
- [111] Wormald R. Primary open angle glaucoma: screening. In: Hitchings RA, ed. *Glaucoma*: BMJ publishing group 2000:16-21.
- [112] Goffman E. Stigma: notes on the management of a spoiled identity. Harmondsworth: Penguin 1963.
- [113] Zola IK. Pathways to the doctor-from person to patient. *Soc Sci Med*. 1973 Sep;7(9):677-89.
- [114] Wilson R, Walker AM, Dueker DK, Crick RP. Risk factors for rate of progression of glaucomatous visual field loss: a computer-based analysis. *Archives of ophthalmology*. 1982 May;100(5):737-41.
- [115] Bury M. Chronic illness as biographical disruption. *Sociology of health & illness*. 1982 Jul;4(2):167-82.
- [116] Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health & illness*. 1983 Jul;5(2):168-95.
- [117] Scott RA. The constuction of conceptions of stigma by professional experts. In: Douglas JD, ed. *Deviance and respectability: The social construction of moral meaning*. New York: Basic Books 1970.
- [118] Tuck MW, Crick RP. Screening for glaucoma: age and sex of referrals and confirmed cases in England and Wales. *Ophthalmic Physiol Opt*. 1992 Oct;12(4):400-4.
- [119] Laidlaw DA, Bloom PA, Hughes AO, Sparrow JM, Marmion VJ. The sight test fee: effect on ophthalmology referrals and rate of glaucoma detection. *Bmj*. 1994 Sep 10;309(6955):634-6.
- [120] Gardner JM. The sight test fee. Need for more cautious analysis. *Bmj*. 1994 Nov 19;309(6965):1370; author reply 2.
- [121] Murdoch IE, Theodossiades JE. The purpose and cost of free sight tests. *Practitioner*. 1998 Dec;242(1593):817.
- [122] Brody BL, Gamst AC, Williams RA, Smith AR, Lau PW, Dolnak D, et al. Depression, visual acuity, comorbidity, and disability associated with age-related macular degeneration. *Ophthalmology*. 2001 Oct;108(10):1893-900; discussion 900-1.
- [123] Walker JG, Anstey KJ, Lord SR. Psychological distress and visual functioning in relation to vision-related disability in older individuals with cataracts. *British journal of health psychology*. 2006 May;11(Pt 2):303-17.
- [124] Evans JR, Fletcher AE, Wormald RP. Depression and anxiety in visually impaired older people. *Ophthalmology*. 2007 Feb;114(2):283-8.
- [125] Hayman KJ, Kerse NM, La Grow SJ, Wouldes T, Robertson MC, Campbell AJ. Depression in older people: visual impairment and subjective ratings of health. *Optom Vis Sci*. 2007 Nov;84(11):1024-30.
- [126] Burns J, Barrett G, Murdoch I. The experiences of patients with suspect glaucoma. *Ophthalmic Nursing*. 2001;5(3):8-11.
- [127] Patel D, Baker H, Murdoch I. Barriers to uptake of available ophthalmic services among the Asian community in Ealing. *Health Education Journal*. 2006;65(3):267-76.
- [128] Wass A. *Promoting Health: The Primary Health Care Approach*. 2nd Edition ed: Harcourt Saunders 2000.
- [129] Weatherburn P, Henderson L, Reid D, Branigan P, Keogh P, Hickson F. Advertising Awareness: Evaluation of CHAPS national HIV prevention adverts and leaflets targeted at gay men 1996 to 2000: Stigma Research; 2001.

- [130] Livingston PM, McCarty CA, Taylor HR. Knowledge, attitudes, and self care practices associated with age related eye disease in Australia. *Br J Ophthalmol*. 1998 Jul;82(7):780-5.
- [131] McCarty CA. Knowledge and beliefs about common eye disease. *Aust N Z J Ophthalmol*. 1997;25:253-4.
- [132] Hallowell N, Murton F, Statham H, Green JM, Richards MP. Women's need for information before attending genetic counselling for familial breast or ovarian cancer: a questionnaire, interview, and observational study. *Bmj*. 1997 Jan 25;314(7076):281-3.
- [133] Beckman LJ, Harvey SM, Thorburn S, Maher JE, Burns KL. Women's acceptance of the diaphragm: the role of relationship factors. *Journal of sex research*. 2006 Nov;43(4):297-306.
- [134] Patrick ME, Maggs JL, Abar CC. Reasons to have sex, personal goals, and sexual behavior during the transition to college. *Journal of sex research*. 2007 Aug;44(3):240-9.
- [135] Sturges J, Hanrahan K. Comparing telephone and face-to-face qualitative interviewing a research note. *Qualitative Research*. 2004;4(1):107-18.
- [136] Fenig S, Levav I, Kohn R, Yelin N. Telephone vs face-to-face interviewing in a community psychiatric survey. *American journal of public health*. 1993 Jun;83(6):896-8.
- [137] Nicolaas G, Lynn P. Random-digit dialling in the UK: viability revisited. *Journal of Royal Statistical Society A*. 2002;165(Part 2):297-316.
- [138] Nicolaas G. Sampling Issues for Telephone Surveys in Scotland. 2004 [cited; www.bioss.ac.uk/staff/admin/rsse/2003-4/presentations/gerry_nicolaas.ppt]. Available from:
- [139] Green J, Siddall H, Murdoch I. Learning to live with glaucoma: a qualitative study of diagnosis and the impact of sight loss. *Soc Sci Med*. 2002 Jul;55(2):257-67.
- [140] Marmot MG, McDowall ME. Mortality decline and widening social inequalities. *Lancet*. 1986 Aug 2;2(8501):274-6.
- [141] Fraser S, Bunce C, Wormald R, Brunner E. Deprivation and late presentation of glaucoma: case-control study. *Bmj*. 2001 Mar 17;322(7287):639-43.
- [142] RNIB. Older people and eye tests: Don't let age rob you of your sight 2007 [cited 13/02/2008]; Available from: www.rnib.org.uk/xpedio/groups/public/documents/publicwebsite/public_ol_dereyereportp.pdf
- [143] Baker H, Murdoch IE. Can a public health package on glaucoma reach its target population? *Eye*. 2004 May;18(5):478-82.
- [144] Moreira ED, Glasser DB, King R, Duarte FG, Gingell C, Group FT. Sexual difficulties and help-seeking among mature adults in Australia: results from the Global Study of Sexual Attitudes and Behaviours. *Sexual health*. 2008 Sep;5(3):227-34.
- [145] Patel UD, Murdoch IE, Theodossiades J. Glaucoma detection in the community: does ongoing training of optometrists have a lasting effect? *Eye*. 2006 May;20(5):591-4.
- [146] Theodossiades J, Murdoch I. Positive predictive value of optometrist-initiated referrals for glaucoma. *Ophthalmic Physiol Opt*. 1999 Jan;19(1):62-7.

- [147] Theodossiades J, Murdoch I, Cousens S. Glaucoma case finding: a cluster-randomised intervention trial. *Eye*. 2004 May;18(5):483-90.
- [148] Macfarlane GJ, Lunt M, Palmer B, Afzal C, Silman AJ, Esmail A. Determining aspects of ethnicity amongst persons of South Asian origin: the use of a surname-classification programme (Nam Pehchan). *Public health*. 2007 Mar;121(3):231-6.
- [149] Nanchahal K, Mangtani P, Alston M, dos Santos Silva I. Development and validation of a computerized South Asian Names and Group Recognition Algorithm (SANGRA) for use in British health-related studies. *Journal of public health medicine*. 2001 Dec;23(4):278-85.
- [150] DOH. 2008 [cited; <http://www.dh.gov.uk/en/Publichealth/Healthimprovement/index.htm>]. Available from:
- [151] Hillsdon M, Cavill N, Nanchahal K, Diamond A, White IR. National level promotion of physical activity: results from England's ACTIVE for LIFE campaign. *J Epidemiol Community Health*. 2001 Oct;55(10):755-61.
- [152] Jackson DMA, Wills R, Davies J, Meadows K, Singh BM, Wise PH. Public awareness of the symptoms of diabetes mellitus. *Diabetic Medicine*. 1991;8:971-2.
- [153] Singh BM, Prescott JJ, Guy R, Walford S, Murphy M, Wise PH. Effect of advertising on awareness of symptoms of diabetes among the general public: the British Diabetic Association Study. *Bmj*. 1994 Mar 5;308(6929):632-6.
- [154] Oakley A, Fullerton D, Holland J, Arnold S, France-Dawson M, Kelley P, et al. Sexual health education interventions for young people: a methodological review. *Bmj*. 1995 Jan 21;310(6973):158-62.
- [155] Sommer A, Tielsch JM, Katz J, Quigley HA, Gottsch JD, Javitt JC, et al. Racial differences in the cause-specific prevalence of blindness in east Baltimore. *N Engl J Med*. 1991 Nov 14;325(20):1412-7.
- [156] Tielsch JM, Sommer A, Katz J, Royall RM, Quigley HA, Javitt J. Racial variations in the prevalence of primary open-angle glaucoma. The Baltimore Eye Survey. *Jama*. 1991 Jul 17;266(3):369-74.
- [157] Baker H, Ntim-Amponsah C, Murdoch IE. A survey of patients attending an eye clinic in Ghana. *Journal of telemedicine and telecare*. 2007;13(8):397-400.

RESEARCH SUPPORT AND COMMERCIAL INTERESTS

This study was supported by Guide Dogs for the Blind Association ophthalmic research grant: Fre12102 **OR2002-02C**. Donations were also made by Guide Dogs for the Blind Association Communications Department, Pfizer and the International Glaucoma Association. The author has no commercial interest in any aspect of this thesis.

APPENDIX A

GLAUCOMA KNOWLEDGE QUESTIONNAIRE

Glaucoma Ealing Questionnaire

JN 45102641

CALLS RECORD – use to record all calls and log appointments

CALL NO.	DAY, DATE AND TIME	R E S U L T
1	Day/Date Time: Outcome of the call (e.g. GCB/Refused etc)	
2	Day/Date Time: Outcome of the call (e.g. GCB/Refused etc)	
3	Day/Date Time: Outcome of the call (e.g. GCB/Refused etc)	
4	Day/Date Time: Outcome of the call (e.g. GCB/Refused etc)	
5	Day/Date Time: Outcome of the call (e.g. GCB/Refused etc)	

INTERVIEWER NAME: _____
DATE: _____
INTERVIEWER ID / NUMBER: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
CATI ID / SERIAL NUMBER: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
RESPONDENT NAME: _____
RESPONDENT TELEPHONE NUMBER: _____
PAPER SERIAL NUMBER: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

Glaucoma Ealing Questionnaire

SECTION 1 CHECKING QUOTAS

Good afternoon/evening, my name iscalling from The Operations Centre on behalf of BMRB Social Research. We are conducting a research project on behalf of University College London and Ealing Hospital, investigating health issues and health awareness in the Borough of Ealing. Your household has been chosen as one of a representative sample living in the borough of Ealing. Your household's participation is vital to ensure a fair representation. The interview will last no longer than 15 minutes. You are free not to answer any questions that worry you and all replies will be treated in the strictest confidence. Your help would be appreciated, would you have time at present to help?

Q.1 We are interested in speaking to people of certain ages. Before we start can I just check what age you were last birthday?

SINGLE CODE

INTERVIEWER: CHECK WITH SUPERVISOR IF AGE AND GENDER ARE IN QUOTA

Type in age in years..... 1 **GO TO Q2a**
 Refused..... ☐ 2 **GO TO Q2**

IF REFUSED TO GIVE AGE

Q.2 Please could you tell me which of the following bands your age falls in?

READ OUT. SINGLE CODE

Under 20.....	<input type="checkbox"/> 1	TERMINATE INTERVIEW – THANK AND CLOSE
20-29 years	<input type="checkbox"/> 2	TERMINATE INTERVIEW – THANK AND CLOSE
30-39 years	<input type="checkbox"/> 3	TERMINATE INTERVIEW – THANK AND CLOSE
40-44 years	<input type="checkbox"/> 4	GO TO Q2a
45-54 years	<input type="checkbox"/> 5	GO TO Q2a
55-59 years	<input type="checkbox"/> 6	GO TO Q2a
60-64 years	<input type="checkbox"/> 7	GO TO Q2a
65-69 years	<input type="checkbox"/> 8	GO TO Q2a
70-74 years	<input type="checkbox"/> 9	GO TO Q2a
75-79 years	<input type="checkbox"/> 10	GO TO Q2a
80+ years	<input type="checkbox"/> 11	GO TO Q2a
Refused.....	<input type="checkbox"/> 12	TERMINATE INTERVIEW – THANK AND CLOSE

IF AGED UNDER 40 OR REFUSED THANK AND CLOSE

CHECK IF THERE ARE OTHER RESPONDENTS IN THE HOUSEHOLD WHO ARE ALSO OVER THE AGE OF 40 YEARS – IF YES THEN USE THE MOST RECENT BIRTHDAY RULE TO SELECT THE RESPONDENT TO INTERVIEW. IF THE ELIGIBLE RESPONDENT REFUSES TO HELP WITH THE SURVEY TERMINATE THE CALL AND CODE AS ‘REFUSED – ELIGIBLE RESPONDENT’.

WRITE IN RESPONDENT NAME: _____

Glaucoma Ealing Questionnaire

ASK ALL RESPONDENTS SINGLE CODE

Q2a. Please could I take the first part of your postcode? READ OUT IF NECESSARY

- | | | |
|------------------|-----------------------------|-----------|
| NW10 | <input type="checkbox"/> 1 | GO TO Q2c |
| UB1 | <input type="checkbox"/> 2 | GO TO Q3 |
| UB2 | <input type="checkbox"/> 3 | GO TO Q2c |
| UB5 | <input type="checkbox"/> 4 | GO TO Q2c |
| UB6 | <input type="checkbox"/> 5 | GO TO Q3 |
| W3 | <input type="checkbox"/> 6 | GO TO Q2c |
| W4 | <input type="checkbox"/> 7 | GO TO Q2c |
| W5 | <input type="checkbox"/> 8 | GO TO Q2c |
| W7 | <input type="checkbox"/> 9 | GO TO Q3 |
| W13 | <input type="checkbox"/> 10 | GO TO Q3 |
| Don't know | <input type="checkbox"/> 11 | GO TO Q2b |

ASK Q2B IF CODE 11 AT Q2A SINGLE CODE

Q.2b Do you live in the Borough of Ealing?

- | | | |
|------------------|----------------------------|---|
| Yes..... | <input type="checkbox"/> 1 | GO TO Q3 |
| No | <input type="checkbox"/> 2 | THANK AND CLOSE CODE AS POSTCODE INELIGIBLE |
| Don't know | <input type="checkbox"/> 3 | THANK AND CLOSE CODE AS POSTCODE INELIGIBLE |
| Refused | <input type="checkbox"/> 4 | THANK AND CLOSE CODE REFUSED HOUSEHOLD INFO |

IF RESPONDENT HAS A BODERLINE POSTCODE (THESE ARE: W4, UB2 AND NW10) ASK Q2.C SINGLE CODE

Q.2c Please can I take your full postcode?

**WRITE IN FULL POSTOCODE - TYPE INTO DATABASE TO CHECK
ELIGIBILITY FOR IF THE RESPONDENT LIVES IN THE BOROUGH OF
EALING**

- | | | |
|------------------|----------------------------|-----------|
| Don't know | <input type="checkbox"/> 2 | GO TO Q2d |
| Refused | <input type="checkbox"/> 3 | GO TO Q2d |

ASK Q2D IF CODE 2/3 AT Q2C SINGLE CODE

Q.2d Do you live in the Borough of Ealing?

- | | | |
|------------------|----------------------------|---|
| Yes..... | <input type="checkbox"/> 1 | GO TO Q3 |
| No | <input type="checkbox"/> 2 | THANK AND CLOSE CODE AS POSTCODE INELIGIBLE |
| Don't know | <input type="checkbox"/> 3 | THANK AND CLOSE CODE AS POSTCODE INELIGIBLE |
| Refused | <input type="checkbox"/> 4 | THANK AND CLOSE CODE REFUSED HOUSEHOLD INFO |

Glaucoma Ealing Questionnaire

SECTION 2 – BEHAVIOUR

Q.3 CODE SEX FROM VOICE

SINGLE CODE

- Male..... ☐ 1 GO TO Q4
- Female..... ☐ 2 GO TO Q4
- Don't know..... ☐ 3 GO TO Q4

L.1 Code language interview is conducted in

- English..... ☐ 1 GO TO Q.4
- Hindi..... ☐ 2 CATI WILL SKIP TO Q33, LEAVE THE SCREEN AT Q33
AND USE THE PAPER QUESTIONNAIRE TO ASK THE RESPONDENT Q4 ONWARDS. ONCE YOU GET TO Q33 USE CATI TO
HELP YOU WITH THE ROUTING FOR THE HOUSEHOLD REFERENCE PERSON.

CONDUCT INTERVIEW ON PAPER FROM Q4 TO Q32.

Q.4 Can I check which of these medical tests or checks you have had in the last 12 months?

READ OUT. MULTI CODE

- Dental check up..... ☐ 1
- Eye test..... ☐ 2
- Blood pressure check..... ☐ 3
- Cholesterol check..... ☐ 4
- None of these/Null..... ☐ 5
- Don't know..... ☐ 6
- Refused..... ☐ 7 ALL GO TO FILTER AT Q5

IF NOT HAD AN EYE TEST AT Q.4 (NOT CODE 3 AT Q.4) ASK Q.5

Q.5 When was the last time you had an eye test?

SINGLE CODE

- Less than two years ago..... ☐ 1
- 2-5 years ago..... ☐ 2
- Over 5 years ago..... ☐ 3
- Don't know..... ☐ 4 ALL GO TO Q6

Glaucoma Ealing Questionnaire

SECTION 3 – GENERAL AWARENESS

Q.6 Can you let me know which of these diseases or conditions you have heard of?

READ OUT. MULTI CODE

- | | | | |
|----------------------------|--------------------------|----|--|
| Psoriasis..... | <input type="checkbox"/> | 1 | |
| Cataract..... | <input type="checkbox"/> | 2 | IF NOT TICKED CODE 2 GO TO Q7. IF TICKED CODE 2 SKIP TO Q8 |
| Arthritis | <input type="checkbox"/> | 3 | |
| Diabetic eye disease..... | <input type="checkbox"/> | 4 | |
| Glaucoma..... | <input type="checkbox"/> | 5 | |
| Alzheimer's | <input type="checkbox"/> | 6 | |
| Macular degeneration | <input type="checkbox"/> | 7 | |
| Tinnitus..... | <input type="checkbox"/> | 8 | |
| Multiple sclerosis..... | <input type="checkbox"/> | 9 | |
| None of these/Null..... | <input type="checkbox"/> | 10 | |
| Don't know | <input type="checkbox"/> | 11 | GO TO FILTER AT Q7 |

IF NOT HEARD OF CATARACT (NOT CODE 2 AT Q.6)

Q.7 Can I just check have you heard of cataract?

SINGLE CODE

- | | | | |
|------------------|--------------------------|---|------------------------------|
| Yes..... | <input type="checkbox"/> | 1 | GO TO Q8 AND READ INTRO TEXT |
| No | <input type="checkbox"/> | 2 | GO TO Q11 |
| Don't know | <input type="checkbox"/> | 3 | GO TO Q11 |

Glaucoma Ealing Questionnaire

UNLESS ASKED Q7 = CODE 1, SAY: The first few questions are about cataract.....

ASK Q.8 IF HEARD OF CATARACT AT Q.6 (CODE 2) OR Q.7 (CODE 1). OTHERS SKIP TO Q.11.

Q.8 How did you first hear of cataract?

DO NOT PROMPT.

SINGLE CODE

- | | | | |
|--|--------------------------|----|----------|
| From doctor/GP | <input type="checkbox"/> | 1 | |
| From optician/optometrist | <input type="checkbox"/> | 2 | |
| From another health professional | <input type="checkbox"/> | 3 | |
| From a friend or relative | <input type="checkbox"/> | 4 | |
| Friend or relative diagnosed with it | <input type="checkbox"/> | 5 | |
| From work | <input type="checkbox"/> | 6 | |
| Saw something on leaflet/poster | <input type="checkbox"/> | 7 | |
| Saw something on TV | <input type="checkbox"/> | 8 | |
| Heard something on the radio..... | <input type="checkbox"/> | 9 | |
| Read something in newspaper/magazine | <input type="checkbox"/> | 10 | |
| I am a patient | <input type="checkbox"/> | 11 | |
| Just know about it..... | <input type="checkbox"/> | 12 | |
| Other (specify) | | | 13 |
| Don't know | <input type="checkbox"/> | 14 | |
| Refused | <input type="checkbox"/> | 15 | GO TO Q9 |

ASK Q.9 IF HEARD OF CATARACT AT Q.6 (CODE 2) OR Q.7 (CODE 1).

Q.9 How much do you think you know about cataract?

READ OUT SINGLE CODE

- | | | | |
|---|--------------------------|---|-----------|
| A lot..... | <input type="checkbox"/> | 1 | GO TO Q10 |
| Quite a lot..... | <input type="checkbox"/> | 2 | GO TO Q10 |
| A little..... | <input type="checkbox"/> | 3 | GO TO Q10 |
| Hardly anything..... | <input type="checkbox"/> | 4 | GO TO Q10 |
| Just heard of it (only know name) | <input type="checkbox"/> | 5 | GO TO Q11 |
| Don't know | <input type="checkbox"/> | 6 | GO TO Q11 |

ASK Q.10 IF NOT JUST HEARD OF IT AT Q.9 (ALL THOSE WHO TICKED CODES 1,2,3 AND 4 AT Q.9 SHOULD ANSWER Q.10)

Q.10 What do you think a cataract is? Just tell me in your own words.

OPEN ENDED QUESTION. PROBE FULLY.

WRITE IN:.....

Glaucoma Ealing Questionnaire

.....

.....

.....

.....

.....

.....

.....

Don't know..... ☐ 2

Refused..... ☐ 3

ALL GO TO Q11 FILTER AND READ INTRO TEXT

SECTION 4 – GLAUCOMA AWARENESS

TO ALL

Next I would like you to think about glaucoma.

CHECK BACK TO Q.6. IF NOT HEARD OF GALUCOMA AT Q.6 (NOT CODE 5) ASK Q.11.

IF HEARD OF GLAUCOMA AT Q.6 SKIP TO Q.12

SINGLE CODE

Q.11 Can I just check have you heard of glaucoma?

Yes..... ☐ 1

No..... ☐ 2

Don't know..... ☐ 3

GO TO Q12

GO TO Q25a

GO TO Q25a

Glaucoma Ealing Questionnaire

**ASK Q.12 IF HEARD OF GLAUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1). OTHERS
SKIP TO Q25A ON PAGE 14**

Q.12 How did you first hear of glaucoma?

SINGLE CODE. DO NOT PROMPT.

- | | | |
|--|-----------------------------|-----------|
| From doctor/GP | <input type="checkbox"/> 1 | |
| From optician/optometrist | <input type="checkbox"/> 2 | |
| From another health professional | <input type="checkbox"/> 3 | |
| From a friend or relative | <input type="checkbox"/> 4 | |
| Friend or relative diagnosed with it | <input type="checkbox"/> 5 | |
| From work | <input type="checkbox"/> 6 | |
| Saw something on leaflet/poster | <input type="checkbox"/> 7 | |
| Saw something on TV | <input type="checkbox"/> 8 | |
| Heard something on the radio..... | <input type="checkbox"/> 9 | |
| Read something in newspaper/magazine | <input type="checkbox"/> 10 | |
| I am a patient | <input type="checkbox"/> 11 | |
| Just know about it | <input type="checkbox"/> 12 | |
| Other (specify)..... | | 13 |
| Don't know | <input type="checkbox"/> 14 | |
| Refused | <input type="checkbox"/> 15 | GO TO Q13 |

ASK Q.13 IF HEARD OF GLAUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.13 How much do you think you know about glaucoma?

SINGLE CODE. READ OUT.

- | | | |
|---|----------------------------|-----------|
| A lot..... | <input type="checkbox"/> 1 | GO TO Q14 |
| Quite a lot..... | <input type="checkbox"/> 2 | GO TO Q14 |
| A little..... | <input type="checkbox"/> 3 | GO TO Q14 |
| Hardly anything | <input type="checkbox"/> 4 | GO TO Q14 |
| Just heard of it (only know name) | <input type="checkbox"/> 5 | GO TO Q17 |
| Don't know | <input type="checkbox"/> 6 | GO TO Q17 |

**ASK Q.14 IF NOT JUST HEARD OF GLAUCOMA AT Q.13 (CODES 1,2,3 AND 4
AT Q.13). OTHERS SKIP TO Q.17.**

Q.14 What do you think glaucoma is? Just tell me in your own words.

OPEN ENDED QUESTION. PROBE FULLY.

WRITE IN:.....

Glaucoma Ealing Questionnaire

Don't know ☐ 2

Refused ☐ 3

ALL GO TO Q15 FILTER

ASK Q.15 IF TICKED CODE 1/2/3 OR 4 AT Q.13. OTHERS SKIP TO Q.17.

Q.15 Now can you tell me which of these statements about glaucoma you think are true or false?

**SINGLE CODE. PLEASE ENCOURAGE RESPONDENT TO ANSWER TRUE/FALSE
AND ONLY CODE DON'T KNOW AS A LAST RESORT**

	TRUE	FALSE	DK
Glaucoma causes a loss of peripheral vision	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Glaucoma is caused by an infection of the eye	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
There is more than one type of glaucoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Men are more likely to suffer from glaucoma than women	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
People of African descent are more likely to suffer from glaucoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Glaucoma can be inherited	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Glaucoma can cause permanent blindness	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Glaucoma may be caused by increased pressure in the eye	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
The optic nerves at the back of the eye are affected by glaucoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Glaucoma causes a skin to grow over the inside of the eye	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Generally people do not develop glaucoma until they are over 40	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Headaches are a commonly associated with glaucoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
High blood pressure can lead to glaucoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
You usually know if you have glaucoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

ASK Q.16 IF TICKED CODE 1/2/3 OR 4 AT Q.13.

Q.16 Which of the following statements best describes the treatment of glaucoma?

READ OUT. SINGLE CODE

There is nothing that can be done to treat glaucoma..... ☐ 1

Treatment can halt the progression of glaucoma, but it cannot cure it..... ☐ 2

Glaucoma can be completely cured..... ☐ 3

Don't know ☐ 4 GO TO Q17 FILTER

Glaucoma Ealing Questionnaire

ASK Q.17 IF HEARD OF GALUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.17 Have you ever had the pressure checked in your eyes? The most common way this is done is with a puff of air.

SINGLE CODE

- Yes..... ☐ 1
No..... ☐ 2
Don't know..... ☐ 3 GO TO Q18 FILTER

ASK Q.18 IF HEARD OF GALUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.18 Another test is a visual field test. This involves responding to a series of flashing lights. Have you ever had this test for glaucoma?

SINGLE CODE

- Yes..... ☐ 1
No..... ☐ 2
Don't know..... ☐ 3 GO TO Q19 FILTER

ASK Q.19 IF HEARD OF GALUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.19 Can you tell me whether or not you yourself have glaucoma?

SINGLE CODE

- Yes- told that I have glaucoma..... ☐ 1
Yes – told that I might have glaucoma..... ☐ 2
No..... ☐ 3
Don't know..... ☐ 4 GO TO Q20 FILTER

ASK Q.20 IF HEARD OF GALUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.20 Do you know anybody else who has glaucoma?

SINGLE CODE

- Yes..... ☐ 1 GO TO Q21 FILTER
No..... ☐ 2 GO TO Q22 FILTER
Don't know..... ☐ 3 GO TO Q22 FILTER

Glaucoma Ealing Questionnaire

ASK Q.21 IF CODED 1 AT Q20 AND HAS HEARD OF GLAUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1). OTHERS SKIP TO Q22 FILTER.

Q.21 Who do you know that has glaucoma?

MULTI CODE. READ OUT.

- | | | | |
|----------------------|--------------------------|----|------------------|
| Mother..... | <input type="checkbox"/> | 1 | |
| Father..... | <input type="checkbox"/> | 2 | |
| Brother/sister..... | <input type="checkbox"/> | 3 | |
| Grandparent..... | <input type="checkbox"/> | 4 | |
| Sons/daughters..... | <input type="checkbox"/> | 5 | |
| Other relative..... | <input type="checkbox"/> | 6 | |
| Friend..... | <input type="checkbox"/> | 7 | |
| Work colleague..... | <input type="checkbox"/> | 8 | |
| Other (Specify)..... | | | 9 |
| Don't know..... | <input type="checkbox"/> | 10 | GO TO Q22 FILTER |

ASK Q.22 IF HEARD OF GLAUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.22 Can I just check, do you have a family history of glaucoma?

SINGLE CODE

- | | | | |
|-----------------|--------------------------|---|------------------|
| Yes..... | <input type="checkbox"/> | 1 | |
| No..... | <input type="checkbox"/> | 2 | |
| Don't know..... | <input type="checkbox"/> | 3 | GO TO Q23 FILTER |

ASK Q.23 IF HEARD OF GALUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.23 Have you seen, heard or read any advertising or publicity recently about glaucoma?

SINGLE CODE

- | | | | |
|-----------------|--------------------------|---|------------------|
| Yes..... | <input type="checkbox"/> | 1 | GO TO Q24 |
| No..... | <input type="checkbox"/> | 2 | GO TO Q25 FILTER |
| Don't know..... | <input type="checkbox"/> | 3 | GO TO Q25 FILTER |

Glaucoma Ealing Questionnaire

ASK Q.24 IF SEEN/HEARD/READ PUBLICITY OR ADVERTISING (CODE 1 AT Q.23)

Q.24 Where did you see, hear or read this advertising or publicity about glaucoma?

MULTI CODE. DO NOT PROMPT

- | | | |
|--|--------------------------|------------------|
| Television programme | <input type="checkbox"/> | 1 |
| Television advert | <input type="checkbox"/> | 2 |
| Radio programme | <input type="checkbox"/> | 3 |
| Radio advert..... | <input type="checkbox"/> | 4 |
| National newspaper advert | <input type="checkbox"/> | 5 |
| National newspaper article | <input type="checkbox"/> | 6 |
| Local newspaper advert | <input type="checkbox"/> | 7 |
| Local newspaper article | <input type="checkbox"/> | 8 |
| Magazine advert | <input type="checkbox"/> | 9 |
| Magazine article | <input type="checkbox"/> | 10 |
| Posters at doctor's/dentist's surgery/ hospital/ chemist..... | <input type="checkbox"/> | 11 |
| Leaflets at doctor's/dentist's surgery/ hospital/ chemist..... | <input type="checkbox"/> | 12 |
| Posters on billboards..... | <input type="checkbox"/> | 13 |
| Posters on bus shelters | <input type="checkbox"/> | 14 |
| Website/internet..... | <input type="checkbox"/> | 15 |
| Other (code and type in)..... | | 16 |
| Don't know | <input type="checkbox"/> | 17 |
| None of these /Null..... | <input type="checkbox"/> | 18 ALL GO TO Q25 |

Glaucoma Ealing Questionnaire

ASK Q.25 IF HEARD OF GLAUCOMA AT Q.6 (CODE 5) OR Q.11 (CODE 1)

Q.25 Can I just check, have you seen, heard or read any advertising or publicity about glaucoma in any of these places?

READ OUT ALL THOSE NOT MENTIONED AT Q24. MULTI CODE

- | | | |
|--|--------------------------|-------------------|
| Television programme | <input type="checkbox"/> | 1 |
| Television advert | <input type="checkbox"/> | 2 |
| Radio programme | <input type="checkbox"/> | 3 |
| Radio advert..... | <input type="checkbox"/> | 4 |
| National newspaper advert | <input type="checkbox"/> | 5 |
| National newspaper article | <input type="checkbox"/> | 6 |
| Local newspaper advert | <input type="checkbox"/> | 7 |
| Local newspaper article | <input type="checkbox"/> | 8 |
| Magazine advert | <input type="checkbox"/> | 9 |
| Magazine article | <input type="checkbox"/> | 10 |
| Posters at doctor's/dentist's surgery/ hospital/ chemist..... | <input type="checkbox"/> | 11 |
| Leaflets at doctor's/dentist's surgery/ hospital/ chemist..... | <input type="checkbox"/> | 12 |
| Posters on billboards..... | <input type="checkbox"/> | 13 |
| Posters on bus shelters | <input type="checkbox"/> | 14 |
| Website/internet..... | <input type="checkbox"/> | 15 |
| Don't know | <input type="checkbox"/> | 16 |
| None of these | <input type="checkbox"/> | 17 ALL GO TO Q25a |

SECTION 5- CLASSIFICATION

ASK ALL

Q.25a What local radio stations do you listen to?

PROBE FULLY: Which others? MULTI CODE.

- | | | |
|---------------------------------|--------------------------|----|
| BBC Asian Network..... | <input type="checkbox"/> | 1 |
| BBC local | <input type="checkbox"/> | 2 |
| Capital FM..... | <input type="checkbox"/> | 3 |
| Capital Gold..... | <input type="checkbox"/> | 4 |
| Classic FM..... | <input type="checkbox"/> | 5 |
| Heart | <input type="checkbox"/> | 6 |
| Invicta FM | <input type="checkbox"/> | 7 |
| Jazz FM | <input type="checkbox"/> | 8 |
| Kiss 100..... | <input type="checkbox"/> | 9 |
| LBC 1152 AM | <input type="checkbox"/> | 10 |
| Magic FM..... | <input type="checkbox"/> | 11 |
| News Direct 97.3 FM | <input type="checkbox"/> | 12 |
| Radio 1 | <input type="checkbox"/> | 13 |
| Radio 2 | <input type="checkbox"/> | 14 |
| Radio 3 | <input type="checkbox"/> | 15 |
| Radio 4 | <input type="checkbox"/> | 16 |
| Radio 5 Live | <input type="checkbox"/> | 17 |
| Sunrise Radio..... | <input type="checkbox"/> | 18 |
| talkSPORT..... | <input type="checkbox"/> | 19 |
| Team Talk 252..... | <input type="checkbox"/> | 20 |
| Virgin..... | <input type="checkbox"/> | 21 |
| XFM..... | <input type="checkbox"/> | 22 |
| Other (specify)..... | | 23 |
| Don't listen to the radio | <input type="checkbox"/> | 24 |
| Don't know | <input type="checkbox"/> | 25 |

READ OUT TO ALL: The next set of questions are about you, to ensure we have a representative group from the area. I would like to remind you that there is no obligation to answer all questions if they trouble you.

Q.26 Have you ever worked in the health care field?

READ OUT. SINGLE CODE

Glaucoma Ealing Questionnaire

- Yes – currently work in health care field..... ☐ 1 GO TO Q27
- Yes – worked in health care field in the past..... ☐ 2 GO TO Q27
- No..... ☐ 3 GO TO Q28
- Don't know..... ☐ 4 GO TO Q28

IF EVER WORKED IN HEALTH CARE (CODE 1 OR 2 AT Q.26)

Q.27 In what roles have you worked in the health care field?

MULTI CODE

- Optometrist..... ☐ 1
- Optician..... ☐ 2
- Doctor/Consultant in hospital..... ☐ 3
- GP..... ☐ 4
- Nurse..... ☐ 5
- Health care assistant/auxiliary..... ☐ 6
- Dentist..... ☐ 7
- Pharmacist..... ☐ 8
- Manager..... ☐ 9
- Administrative e.g. receptionist/secretary..... ☐ 10
- Support services e.g. porter, cleaner etc..... ☐ 11
- Other (Specify)..... ☐ 12
- Don't know..... ☐ 13 ALL GO TO Q28

ASK ALL

Q.28 Do any of your close relatives work in the health care field or have they ever worked in the health care field?

SINGLE CODE

- Yes..... ☐ 1
- No..... ☐ 2
- Don't know..... ☐ 3 GO TO Q29

ASK ALL

Q.29 Have you ever worn glasses or contact lenses?

CODE ALL THAT APPLY. MULTI CODE

NOTE: IF USED TO BUT NO LONGER – CODE WHAT USED TO WEAR

- Glasses..... ☐ 1
- Contact lenses..... ☐ 2
- Neither..... ☐ 3
- Don't know..... ☐ 4 GO TO Q30

Glaucoma Ealing Questionnaire

ASK ALL

Q.30 What is the highest level qualification you have ever attained?

SINGLE CODE. READ OUT IF NECESSARY.

- | | | |
|--|--------------------------|----|
| Degree or equivalent..... | <input type="checkbox"/> | 1 |
| Teaching or higher qualification..... | <input type="checkbox"/> | 2 |
| A level or equivalent..... | <input type="checkbox"/> | 3 |
| O level or equivalent..... | <input type="checkbox"/> | 4 |
| CSE or equivalent..... | <input type="checkbox"/> | 5 |
| CSE ungraded..... | <input type="checkbox"/> | 6 |
| City and Guilds | <input type="checkbox"/> | 7 |
| Completed recognized trade apprenticeship | <input type="checkbox"/> | 8 |
| HND | <input type="checkbox"/> | 9 |
| NVQ/GNVQ..... | <input type="checkbox"/> | 10 |
| Clerical or commercial qualifications (e.g. book keeping/typing/commerce)..... | <input type="checkbox"/> | 11 |
| Other qualifications (state) | | 12 |
| Don't know | <input type="checkbox"/> | 13 |
| Refused | <input type="checkbox"/> | 14 |
| Null..... | <input type="checkbox"/> | 15 |

ASK ALL

Q.31 Which of these describes your marital status?

SINGLE CODE. READ OUT.

- | | | | |
|---------------------------------|--------------------------|---|---------------|
| Single..... | <input type="checkbox"/> | 1 | |
| Married/living as married | <input type="checkbox"/> | 2 | |
| Widowed..... | <input type="checkbox"/> | 3 | |
| Divorced..... | <input type="checkbox"/> | 4 | |
| Separated | <input type="checkbox"/> | 5 | |
| Refused..... | <input type="checkbox"/> | 6 | ALL GO TO Q32 |

ASK ALL

Q.32 Including yourself how many people normally live in your household?

SINGLE CODE

- | | | |
|--------------------|--------------------------|---|
| ENTER NUMBER | | 1 |
| Don't know | <input type="checkbox"/> | 2 |
| Refused..... | <input type="checkbox"/> | 3 |

ghouse

Glaucoma Ealing Questionnaire

ASK ALL

Q.32a Which of these best describes your ethnic origin?

SINGLE CODE

- | | | |
|----------------------------------|--------------------------|----|
| White British | <input type="checkbox"/> | 1 |
| White Irish | <input type="checkbox"/> | 2 |
| Any other White background | <input type="checkbox"/> | 3 |
| White and Black Caribbean | <input type="checkbox"/> | 4 |
| White and Black African | <input type="checkbox"/> | 5 |
| White and Asian | <input type="checkbox"/> | 6 |
| Any other mixed background | <input type="checkbox"/> | 7 |
| Indian | <input type="checkbox"/> | 8 |
| Pakistani | <input type="checkbox"/> | 9 |
| Bangladeshi | <input type="checkbox"/> | 10 |
| Any other Asian background | <input type="checkbox"/> | 11 |
| Caribbean | <input type="checkbox"/> | 12 |
| African | <input type="checkbox"/> | 13 |
| Any other Black background | <input type="checkbox"/> | 14 |
| Chinese | <input type="checkbox"/> | 15 |
| Other (specify) | | 16 |
| Don't know | <input type="checkbox"/> | 17 |
| Refused | <input type="checkbox"/> | 18 |

ASK ALL

Q.33 Did the HRP do any paid work in the 7 days ending last Sunday, either as an employee or as self employed?

INCLUDE ANY PAID WORK FOR ANY NUMBER OF HOURS

- | | | | |
|------------------|--------------------------|---|-----------|
| Yes | <input type="checkbox"/> | 1 | GO TO Q43 |
| No | <input type="checkbox"/> | 2 | GO TO Q34 |
| Don't know | <input type="checkbox"/> | 3 | GO TO Q34 |
| Refused | <input type="checkbox"/> | 4 | GO TO Q34 |

ASK ALL WHO DID NOT SAY YES AT Q33

Q.34 Was the HRP on a government scheme for employment training in the 7 days ending last Sunday?

- | | | | |
|------------------|--------------------------|---|-----------|
| Yes | <input type="checkbox"/> | 1 | GO TO Q43 |
| No | <input type="checkbox"/> | 2 | GO TO Q35 |
| Don't know | <input type="checkbox"/> | 3 | GO TO Q35 |
| Refused | <input type="checkbox"/> | 4 | GO TO Q35 |

Qeth

Q33=
qpaid

Q34=
qgovt

Glaucoma Ealing Questionnaire

ASK ALL WHO DID NOT SAY YES AT Q33 AND Q34

Q.35 Did the HRP have a job or business they were away from in the 7 days ending last Sunday?
IF ON HOLIDAY FROM JOB, ON MATERNITY LEAVE OR SICK LEAVE ETC.,
CODE AS 'YES', SO LONG AS RESPONDENT HAS GUARANTEED JOB TO GO
BACK TO.

- | | | |
|--|----------------------------|-----------|
| Yes | <input type="checkbox"/> | GO TO Q43 |
| No | <input type="checkbox"/> 2 | GO TO Q36 |
| Waiting to take up new job/business already obtained | <input type="checkbox"/> 3 | GO TO Q38 |
| Don't know | <input type="checkbox"/> 4 | GO TO Q36 |
| Refused | <input type="checkbox"/> 5 | GO TO Q36 |

Q35=
Qaway

ASK ALL WHO DID NOT SAY YES AT Q33 AND Q34 AND Q35

Q.36 Did the HRP do any UNPAID work for any business owned by the HRP or a relative in the 7
days ending last Sunday?

INCLUDE SPOUSE/COHABITEE

- | | | |
|------------|----------------------------|-----------|
| Yes | <input type="checkbox"/> 1 | GO TO Q43 |
| No | <input type="checkbox"/> 2 | GO TO Q37 |
| Don't know | <input type="checkbox"/> 3 | GO TO Q37 |
| Refused | <input type="checkbox"/> 4 | GO TO Q37 |

Q36=
Qunpaid

ASK ALL WHO DID NOT SAY YES AT ANY OF Q.33 – Q.36

Q.37 Thinking of the FOUR WEEKS ending last Sunday, was the HRP looking for any kind of paid
work or government training scheme at any time in those 4 weeks?

- | | | |
|--|----------------------------|-----------|
| Yes | <input type="checkbox"/> 1 | GO TO Q38 |
| No | <input type="checkbox"/> 2 | GO TO Q39 |
| Waiting to take up new job/business already obtained | <input type="checkbox"/> 3 | GO TO Q38 |
| Don't know | <input type="checkbox"/> 4 | GO TO Q39 |
| Refused | <input type="checkbox"/> 5 | GO TO Q39 |

Q37=
Qlook

**ASK ALL WHO SAID YES OR WAITING TO TAKE UP A JOB AT Q.35 OR
WAITING TO TAKE UP A JOB AT Q.37**

Q.38 If a job or a place on a government scheme had been available LAST week, would the HRP
have been able to start WITHIN 2 WEEKS?

- | | | |
|------------|----------------------------|-----------|
| Yes | <input type="checkbox"/> 1 | GO TO Q41 |
| No | <input type="checkbox"/> 2 | GO TO Q39 |
| Don't know | <input type="checkbox"/> 3 | GO TO Q39 |
| Refused | <input type="checkbox"/> 4 | GO TO Q39 |

Q38=
Qlast

Glaucoma Ealing Questionnaire

ASK ALL WHO DID NOT SAY YES AT Q.33 – Q.36 AND ANSWERED NO/DON'T KNOW/REFUSED AT Q.37 OR Q.38)

Q.39 What was the MAIN reason the HRP did not look for work in the LAST 4 WEEKS?

- | | | |
|----------------------------------|----------------------------|-----------------------------|
| Student..... | <input type="checkbox"/> 1 | GO TO Q42 FILTER |
| Looking after family/home..... | <input type="checkbox"/> 2 | ALL OTHERS GO TO Q40 FILTER |
| Temporarily sick or injured..... | <input type="checkbox"/> 3 | |
| Long term sick or disabled..... | <input type="checkbox"/> 4 | |
| Retired from paid work..... | <input type="checkbox"/> 5 | |
| Other reasons (specify) | | 6 |
| Don't know..... | <input type="checkbox"/> 7 | |
| Refused..... | <input type="checkbox"/> 8 | |

Q39=
Qreason

ASK ALL WHO SAID WAITING TO TAKE UP A JOB/BUSINESS ALREADY OBTAINED AT Q.37 AND NO AT Q.38

Q.40 What was the MAIN reason the HRP would not have been able to start WITHIN 2 WEEKS?

- | | | |
|----------------------------------|----------------------------|-----------------------------|
| Student..... | <input type="checkbox"/> 1 | GO TO Q42 FILTER |
| Looking after family/home..... | <input type="checkbox"/> 2 | ALL OTHERS GO TO Q41 FILTER |
| Temporarily sick or injured..... | <input type="checkbox"/> 3 | |
| Long term sick or disabled..... | <input type="checkbox"/> 4 | |
| Retired from paid work..... | <input type="checkbox"/> 5 | |
| Other reasons (specify) | | 6 |
| Don't know..... | <input type="checkbox"/> 7 | |
| Refused..... | <input type="checkbox"/> 8 | |

Q40=
Qreas2

ASK ALL UNLESS SAID STUDENT AT Q.39 OR Q.40

Q.41 Can I just check, is the HRP a full-time student at college or university?

- | | | |
|-----------------|----------------------------|-----------------------------------|
| Yes..... | <input type="checkbox"/> 1 | GO TO Q45 AND READ OUT INTRO TEXT |
| No..... | <input type="checkbox"/> 2 | GO TO Q52 / RECON |
| Don't know..... | <input type="checkbox"/> 3 | GO TO Q52 / RECON |
| Refused..... | <input type="checkbox"/> 4 | GO TO QRECON |

Q41=
Qstudent

ASK IF HRP DID NOT ANSWER YES AT Q.33 – Q.36

Q.42 Can I just check, has the HRP ever had a paid job?

- | | | |
|-----------------------------------|----------------------------|--------------------|
| Had a job in the past..... | <input type="checkbox"/> 1 | GO TO Q45 |
| Has never worked in paid job..... | <input type="checkbox"/> 2 | GO TO Q52 / QRECON |
| Don't know..... | <input type="checkbox"/> 3 | GO TO Q52 / RECON |
| Refused..... | <input type="checkbox"/> 4 | GO TO Q52 / RECON |

Q42=
Qever

IF HAD A JOB IN THE PAST, READ OUT: I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT THE LAST MAIN JOB THE HRP DID.

NOTE – ALL QUESTIONS ARE WORDED AS IF THE HRP IS STILL IN WORK – FOR THOSE WITH A JOB IN THE PAST YOU MAY NEED TO REMIND THEM AT EACH QUESTION THAT WE ARE TALKING ABOUT THE LAST JOB

Glaucoma Ealing Questionnaire

ASK ALL WHO SAID YES AT Q.33- Q.36 FOR CODES 1/2/3

Q.43 In the HRP's (main) job are they working full-time or part-time?

NOTE: IF RESPONDENT IN DOUBT, TAKE THEIR VIEW OF WHETHER JOB IS FULL- OR PART-TIME

- | | | |
|-----------------|----------------------------|-----------|
| Full time | <input type="checkbox"/> 1 | GO TO Q44 |
| Part time..... | <input type="checkbox"/> 2 | GO TO Q44 |
| Don't know..... | <input type="checkbox"/> 3 | GO TO Q44 |
| Refused..... | <input type="checkbox"/> 4 | GO TO Q44 |

Q43=
Qmain

ASK ALL WHO SAID YES AT Q.33- Q.36 FOR CODES 1/2/3

Q.44 How many hours per week does the HRP usually work in their main job or business?

Please include overtime but exclude meal breaks.

PROBE FOR ESTIMATE RECORD TO NEAREST HOUR

Range 0-100 WRITE IN.....1

- | | | |
|------------------|----------------------------|-----------|
| Don't know | <input type="checkbox"/> 2 | GO TO Q45 |
| Refused..... | <input type="checkbox"/> 3 | GO TO Q45 |

Q44=
Qhours

ASK ALL WHO SAID YES AT Q.33- Q.36 FOR CODES 1/2/3 OR Q.42 = CODE 1

Q.45 What does the firm/organisation they work for mainly make or do at the place where they work?

PROBE FULLY RECORD VERBATIM

WRITE IN.....1

- | | | |
|------------------|----------------------------|-----------|
| Don't know | <input type="checkbox"/> 2 | GO TO Q46 |
| Refused..... | <input type="checkbox"/> 3 | GO TO Q46 |

Q45=
Qmake

ASK ALL WHO SAID YES AT Q.33- Q.36 FOR CODES 1/2/3 OR Q.42 = CODE 1

Q.46 What is the HRP's (main) job?

PROBE FULLY ENTER JOB TITLE

WRITE IN.....1

- | | | |
|------------------|----------------------------|-----------|
| Don't know | <input type="checkbox"/> 2 | GO TO Q47 |
| Refused..... | <input type="checkbox"/> 3 | GO TO Q47 |

Q46=
Qwhat

ASK ALL WHO SAID YES AT Q.33- Q.36 FOR CODES 1/2/3 OR Q.42 = CODE 1

Q.47 What do they mainly do in their job?

PROBE FULLY

CHECK SPECIAL QUALIFICATIONS/TRAINING NEEDED TO DO THE JOB

WRITE IN:.....

- | | | |
|------------------|----------------------------|-----------|
| Don't know | <input type="checkbox"/> 2 | GO TO Q48 |
| Refused | <input type="checkbox"/> 3 | GO TO Q48 |

Q47=
Qdo

Q48=
Qemplo
Y

Glaucoma Ealing Questionnaire

ASK ALL WHO SAID YES AT Q.33- Q.36 FOR CODES 1/2/3 OR Q.42 = CODE 1
Q.48 Are they working as an employee or were they self-employed?

- | | | |
|---------------------|----------------------------|-----------|
| Employee | <input type="checkbox"/> 1 | GO TO Q49 |
| Self-employed | <input type="checkbox"/> 2 | GO TO Q51 |
| Don't know | <input type="checkbox"/> 3 | GO TO Q49 |
| Refused | <input type="checkbox"/> 4 | GO TO Q49 |

ASK ALL WHO SAID EMPLOYEE AT Q.48 (CODE 1)
Q.49 Do they have any managerial duties or are they supervising any other employees?

- | | | |
|------------------------------|----------------------------|-----------|
| Manager | <input type="checkbox"/> 1 | GO TO Q50 |
| Foreman or supervisor | <input type="checkbox"/> 2 | GO TO Q50 |
| Not manager/supervisor | <input type="checkbox"/> 3 | GO TO Q50 |
| Don't know | <input type="checkbox"/> 4 | GO TO Q50 |
| Refused | <input type="checkbox"/> 5 | GO TO Q50 |

ASK ALL WHO SAID EMPLOYEE AT Q.48 (CODE 1)
Q.50 How many employees are there at the place where they work?
INTERVIEWING BRIEFING POINT: THIS IS AT THE ESTABLISHMENT ADDRESS/SITE NOT THE WHOLE ORGANISATION (IF MULTISITE)

- | | | |
|------------------------|----------------------------|----------------------|
| WRITE IN NUMBER: | <input type="checkbox"/> 1 | ALL GO TO Q53 FILTER |
| Don't Know | <input type="checkbox"/> 2 | |
| Refused | <input type="checkbox"/> 3 | |

ASK ALL WHO SAID SELF-EMPLOYED AT Q.48 (CODE 2)
Q.51 Are they working on their own or do they have employees?

- | | | |
|--|----------------------------|-----------|
| On own/with partner(s) but no employees..... | <input type="checkbox"/> 1 | GO TO Q53 |
| With employee..... | <input type="checkbox"/> 2 | GO TO Q52 |
| Don't Know | <input type="checkbox"/> 3 | GO TO Q53 |
| Refused | <input type="checkbox"/> 4 | GO TO Q53 |

ASK ALL WHO SAID WITH EMPLOYEES AT Q.51 (CODE 2)
Q.52 How many people do they employ at the place where they work?
INTERVIEWING BRIEFING POINT: THIS IS AT THE ESTABLISHMENT ADDRESS/SITE NOT THE WHOLE ORGANISATION (IF MULTISITE)

- | | | |
|------------------|----------------------------|----------------------|
| 1-24..... | <input type="checkbox"/> 1 | |
| 25 or more | <input type="checkbox"/> 2 | |
| Don't Know | <input type="checkbox"/> 3 | |
| Refused | <input type="checkbox"/> 4 | ALL GO TO Q53 FILTER |

ASK IF RESPONDENT IS NOT HRP
Q.53 Which of these best describes your working status at the moment

- | | |
|--|----------------------------|
| Working in a paid job (30+ hours) | <input type="checkbox"/> 1 |
| Working in a paid job (8-29 hours) | <input type="checkbox"/> 2 |
| Working in a paid job (less than 8 hours)..... | <input type="checkbox"/> 3 |
| Self employed | <input type="checkbox"/> 4 |
| Not in paid employment/looking after house or home | <input type="checkbox"/> 5 |
| Full time student at university/college | <input type="checkbox"/> 6 |
| Unemployed | <input type="checkbox"/> 7 |
| Retired from paid employment..... | <input type="checkbox"/> 8 |

Q49=
Qmanag
e

Q50=
Qnumbe
r

Q51=
own

Q52=
Qpeopl
e

Q53=
Qwork

Glaucoma Ealing Questionnaire

<p>ASK ALL</p> <p>Q54. QRECON. We may want to re-contact some people about this subject in the future.</p> <p>Would it be alright to re-contact you?</p> <p>Yes <input type="checkbox"/> 1</p> <p>No <input type="checkbox"/> 2</p> <p>Don't know <input type="checkbox"/> 3</p> <p>That's the last of the questions I have to ask you. Thank you for your help in completing this survey. If you have any questions or concerns about Glaucoma there is a national helpline you can contact for the International Glaucoma Association Sight Line on 020 7737 3265</p>	<p>Q54= Qrecon</p>
---	------------------------

APPENDIX B

PEER REVIEWED PUBLICATIONS ORIGINATING DIRECTLY FROM THIS THESIS



PERGAMON

Social Science & Medicine 55 (2002) 257–267

SOCIAL
SCIENCE
&
MEDICINE

www.elsevier.com/locate/socscimed

Learning to live with glaucoma: a qualitative study of diagnosis and the impact of sight loss

Judith Green^{a,*}, Helen Siddall^b, Ian Murdoch^c

^a Health Services Research Unit, London School of Hygiene & Health, Tropical Medicine, Keppel Street, London WC1E 7HT, UK

^b Department of Epidemiology and International Eye Health, Institute of Ophthalmology & Moorfields Hospital, 11-43 Bath Street, London EC1V 9EL, UK

^c Department of Epidemiology and International Eye Health, Institute of Ophthalmology & Moorfields Hospital, 11-43 Bath Street, London EC1V 9EL, UK

Abstract

Glaucoma is a major cause of preventable sight loss. As there are no obvious symptoms in the early stages, when it is most beneficial to start treatment, the key to reducing undiagnosed glaucoma in the community is better case finding among those at higher risk. This qualitative study aimed to identify triggers to self-referral for glaucoma symptoms in a sample from Britain, and to explore the meaning of symptoms for people living with moderate to severe glaucoma. Participants ($N = 28$) reported low levels of awareness of glaucoma prior to their diagnosis, and had assumed that symptoms were the 'normal' deterioration of eyesight expected with other morbidity or advancing age. As symptoms have a gradual onset, participants had learnt to cope with diminishing sight ability. However, many reported that such coping was 'at a cost', and that managing in a world designed for the well sighted caused problems for activities of everyday living, work and family life. The salience of these problems was shaped primarily by social factors, which framed both the practical consequences of sight loss and their meaning for respondents. Findings from this study suggest health promotion is a priority to increase public awareness of the existence and symptoms of glaucoma among those at high risk, and that more attention could be given to reducing the environmental and social causes of disability.

© 2002 Elsevier Science Ltd. All rights reserved.

Keywords: Glaucoma; Sight loss; Disability; Independence

Introduction

Over 1 million people in the UK are visually impaired, and about one third of those are registered blind or partially sighted (RNIB, 2000). Glaucoma is the third most common cause of blindness registration in the UK, and has an estimated population prevalence of 3% of those over 49 (Mitchell, Smith, Attebo, & Healey, 1996). Particular sub groups in the population are at higher risk, with age, being of Afro-Caribbean descent and a family history all increasing risk (Mitchell et al., 1996; Sommer, Tielsch, & Katz, 1991). The extent of sight loss

in the community is far larger than blindness registration suggests. First, the majority of those diagnosed with glaucoma are not registered blind and second, community surveys in developed countries suggest that only about half of those with glaucoma have been diagnosed (Coffey & Reidy, 1993; Quigley, 1996). Survey research has identified a range of problems that people with glaucoma may face in managing everyday tasks: Nelson, Aspinall and O'Brien (1998), for instance, reported problems with outdoor mobility, glare and lighting, household tasks and personal care. In the UK, over 80% of glaucoma referrals to specialist services result from screening during routine sight tests (Bell & O'Brien, 1997).

A majority of damage from glaucoma is preventable and most of those diagnosed can expect to retain vision

*Corresponding author. Tel.: +44-20-7-927-2024; fax: +44-20-7-580-8183.

E-mail address: judith.green@lshtm.ac.uk (J. Green).

for the duration of their lives with appropriate therapy. Characterised by gradual loss of visual ability as optic nerve damage reduces visual fields, glaucoma is asymptomatic in early stages, but loss of vision is irreversible once it occurs. Given that glaucoma can take five years or more to progress to blindness if untreated (Jay & Murdoch, 1993), and that the development of symptoms is insidious, people with glaucoma learn to adapt to reductions in visual ability. Although such adaptive processes are a feature of many illness and disability experiences, they are a particular challenge for eye disease specialists because many patients do not seek treatment until there is considerable optic nerve damage, when treatment is more difficult. Although the ethical difficulties of running trials of treatment options mean there are few published studies of effectiveness, evidence to date indicates that if diagnosed early, appropriate treatment can potentially preserve sight for the duration of a normal life span. In terms of preventing sight loss from glaucoma, then, early referral for treatment is beneficial, although many do not seek help until some irreversible sight loss has occurred.

The relationship between glaucoma as a disease and the experiences of people who have been diagnosed with glaucoma provides perhaps a classic example of the potential gulf between 'medical' and 'social' models of disability. In terms of the WHO (1980) *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) glaucoma is a disease that causes impairment (optic nerve damage), which in turn causes disability (sight loss or blindness) and handicap (limitations in the fulfilment of social roles). The draft revised version ICIDH-2, the *International Classification of Functioning, Disability and Health* (WHO, 2000) aims to move away from a 'disability as a consequence of disease' model and towards an integrated 'biopsychosocial' model which is universalistic in that it applies to all people, rather than 'the disabled' (Bickenbach et al., 1999). However, the starting point is, inevitably, health and health related domains. From this perspective, the primary key to reducing 'handicap' (or limitations in activity or participation, in ICIDH-2) is preventing disease, or ameliorating its effects. Despite claims that ICIDH-2 does integrate a 'social model' of disability (Bickenbach et al., 1999; Bury, 2000), critics of both ICIDH and ICIDH-2 (see, for example, Barnes 1998; Pfeiffer, 2000) have pointed to the way in which such models both medicalise and individualise the experience of disability, assuming that disease is the root cause of problems faced, and that 'disability' is inherently undesirable, requiring medical intervention to 'repair'.

The Disabled People's Movement has been active in changing the focus of research from diseases, symptoms and physical impairments to the broader social structures that make such symptoms problematic (see, for

example, Shakespeare & Watson, 1997; Barnes, Mercer, & Shakespeare, 1999). These structures include the cultural frameworks which privilege able-bodied 'normality', health and welfare systems that assume that disability such as sight loss is at root an individualised medical problem and built environments that systematically exclude those with disabilities. In short, the 'social model' of disability shifts the question from one of how disease causes disability to how 'society ... disables physically impaired people' (Oliver, 1996, 22), and shifts the problem from a medical one to a political one. From the perspective of the 'social model', the question is not, then, how to reduce the 'burden' of disability from glaucoma, but how to reduce the barriers to full social participation faced by those with sight loss.

Characterised in these extreme terms, the two approaches are difficult to integrate. As Scott (1970) noted over thirty years ago, the boundaries that professionals draw around 'blindness' are to a large extent arbitrary, and there may be little congruence between clinical measurements and experience of visual loss. For instance, the difference between clinical findings of mild to moderate field loss is not reflected in patients' own assessments of visual disability (Nelson et al., 1998). For many patients, co-morbidity reduces the relative significance of eyesight disability as a challenge for daily living, and the quality of the physical and social environment may be a more significant factor than disease progression in the level of disability experienced (Landes & Popay, 1993). Conversely, relatively minor (from a clinical perspective) 'impairment' can result in dramatic declines in self-assessed quality of life, for instance for those whose employment relies on high levels of visual ability.

The meaning of sight loss for any individual clearly depends on a combination of environmental, social and psychological factors, including physical environment, family circumstances, work roles and adaptive responses to symptoms, rather than medically defined measures of disability.

The sociological literature on living with sight loss is relatively limited, but does suggest the importance of framing research within a more social model of disability. In a study of older people with visual impairment in the United States, for instance, Ainlay has written eloquently of the 'sighted world that has systematically avoided the world of blindness and segregated those who experience it from the mainstream of life' (Ainlay, 1989, x). In the twenty life histories he collected, there is evidence of a 'double burden' of both coping with a physically disabling environment, and coping with the threat to self identity involved in learning to be visually impaired in a sighted world. Taken for granted tasks (reading instructions, setting the cooker at the right temperature) are disrupted such that

everyday life becomes problematic. At the level of self-identity, vision loss potentially disrupts a secure sense of self in the world, with a new identity having to be incorporated into biography. The reluctance to give up driving reported by many participants illustrated for Ainalay this double burden. Continuing to drive, even when to do so was risky, suggested not only the reliance many have on cars to access goods and services, but also how vital the car is as a symbol of (American) normality. A British needs assessment (Landes & Popay, 1993) echoed this need for a focus on environments to address the needs of older people with visual impairment.

There are, then, two sets of research questions that appear to be irreconcilable. The first arises from a medical model, start with glaucoma as a disease, and address strategies to reduce the impact of disease on individuals, through identifying barriers to early referral and effective medical treatment. The second arises from a more social model. They start with the lived experience of sight loss, and explore how this is made problematic in a cultural environment which prizes good vision (consider the metaphors used to equate eyesight with understanding and knowledge) and a social environment that systematically excludes those with impaired vision. This study began with a question rooted largely within a medical model ('how can we improve case finding for glaucoma in order to reduce blindness in the community?'), but early data collection underscored the importance of a 'social model' perspective which accounted for the experiences of people with sight loss, rather than levels of clinical impairment. A qualitative approach was needed to understand the relationship between the diagnosis of disease, the meaning of symptoms for patients, their impact on everyday life and how they are shaped by social contexts. This study explored the meaning of sight loss for one group of people, those who had been diagnosed with moderate to severe glaucoma, using individual and group interviews. The aims were to identify barriers to self-referral for sight problems, the triggers to the decision to seek professional help and to explore how sight loss from glaucoma impacted on everyday life in a world designed for the sighted.

Methods

Participants

This qualitative study was based on interviews with 28 patients (14 men, 14 women) sampled from two hospitals; one specialist urban eye hospital and one District General Hospital. In addition, several participants provided (at their own suggestion) written notes on their experiences. These were used to inform early interview prompts. Individuals were invited to partici-

pate if they had visual function deficits from severe or moderately severe open angle glaucoma with no other significant ocular pathology. Some were registered, or registerable, blind. Twenty participants were interviewed in in-depth one-to-one interviews. These interviews took a narrative approach, using a series of prompts to allow participants to relate how they first noticed problems with their eyesight, the process of referral to hospital, the impact of symptoms and treatment regimes on their everyday lives and their hopes for the future. Eight patients were interviewed in two groups, in which similar prompts were used. The group interviews provided an opportunity for patients with glaucoma to compare their stories with others' and, in interaction, articulate the particular meanings of symptoms and treatment regimes for themselves. Group interviews proved useful, as many experiences were only identified as related to glaucoma when participants could compare them with the experiences of other participants. Participants ranged in age from 25 to 86 years, and the time since diagnosis of glaucoma ranged from one month to twenty years. Ethical approval was provided by Moorfields Ethics Committee, and all participants gave written consent to participation.

Analysis

All interviews were taped (with permission) and transcribed. In addition, several participants also provided written notes on their experiences, which were used to inform prompts for the interviews. The aim of this study was not to extend sociological theory, but rather to test what contribution existing theory could make in understanding the accounts of those with glaucoma. The study did not, therefore, aim to produce 'grounded theory' from qualitative data, but some of the principles of the constant comparative method (Strauss, 1987) were used to analyse data. This involved 'open coding' the first few transcripts to explore the range of concepts utilised by participants to describe the stages in their experiences of glaucoma, and to start identifying key analytical concepts which would make sense of the trajectories of symptom recognition, diagnosis, treatment and management. This initial coding informed later sampling through generating a set of propositions to 'test' through further data collection. Detailed coding of the whole data set was then carried out by two authors (HS and JG). Excerpts are annotated with the interview number, prefixed by I for one to one interviews and G for group interviews.

Findings

In addressing the research questions about triggers and barriers to self-referral, and the impact of sight loss

on everyday life, this paper focuses on three particular, but inter-connected, aspects of participants' stories about glaucoma. These are: the 'unexpectedness' of the diagnosis; the impact of symptoms on everyday life and the tension between coping with this impact and the management of a 'normal' everyday life ('managing at a cost'). In exploring the meaning of symptoms, and everyday experiences of coping with sight loss, the participants identified more general barriers to referral. These included cultural frameworks of sight disability, which did not easily accommodate 'glaucoma' as a category, and general lack of public awareness of the disease.

The experience of diagnosis: an unexpected label

All respondents in this study experienced the diagnosis of glaucoma, in general, to be a 'surprise': an unexpected explanation for their symptoms, or an unexpected finding on a routine examination. Glaucoma does not cause noticeable sight loss in the early stages, and for some respondents the diagnosis was the first indication that there was something wrong with their eyes. Some recalled a disjunction between clinical findings and their own experience: although tests indicated reduced visual fields, they perceived no problems with vision

The top right [field of vision] was really dark, and they [clinicians] were afraid of it coming down to tunnel vision. But as far as I was concerned, I was seeing perfectly normally. (I6)

It came as a complete surprise. My eyesight, certainly my distance eyesight's always been very good. Still is quite good! (I8)

As one man put it: 'the most dangerous part of your life is the period where you don't notice anything is wrong—there's a defect in your eye. But you don't see anything' (G2). Looking back at the time before diagnosis, respondents recalled a range of eye problems that were, but only in retrospect, seen as early possible symptoms. They included mistiness; difficulty in focusing, particularly in the morning; dimness in one eye; problems with light; seeing 'halos' around lights; general deterioration in visual ability and zigzags across the eyes. However, at times, such symptoms are experienced as part of the range of minor problems that afflict most people from time to time, and are usually easily accommodated as 'normal' signs of ageing, tiredness or the expected deterioration of vision over time. For those with other health, particularly eyesight, problems, the symptoms of glaucoma were particularly hard to distinguish, and many respondents recalled assuming that decreasing visual ability was a result of existing eye problems or other health problems, such as allergies.

Only once they had been diagnosed could problems with sight be re-framed as 'symptoms' of glaucoma. The diagnosis itself attuned the patient to being sensitive to disabilities, and interpreting them as 'unusual' and symptomatic rather than normal deviations from perfect eyesight

I went to the doctor thinking that it was my glasses that had gone weak, and when I went there he told that I had eye pressure. And the next thing I noticed, I couldn't see at night, I started kicking things around. (G1)

For those who did notice that there was an abnormal symptom, the first sign that 'something unusual was happening' was often a minor incident, unremarkable except for it being a sign of something more than general deterioration in their visual ability. Many respondents recalled a particular and, in retrospect at least, 'fateful' moment when it became apparent that there was a specific problem with their field of vision

I went to a flower show, in the local community centre ... and somebody said to me 'isn't that amaryllis absolutely beautiful!', and I looked across the table and I couldn't see an amaryllis. And then I brought my eyes up, and there was the amaryllis! I just hadn't seen it. I was really shocked at that. (I7)

I was reading along and this word, 'Fra Sinatra' leapt out at me, and I thought that's funny, who or what is Fra Sinatra? So I stopped and went back a sentence or so and I went back to have a look and it was Frank Sinatra. The 'nk' had vanished. (I1)

Others were alerted to vision problems when work was affected. One (then a milkman) was first referred to a workplace optician after a number of minor accidents at work, although he had not noticed any deterioration in visual or driving ability himself. Another, a photographer, was alerted when colleagues noticed that one pupil was smaller than the other and when he realised vision in one eye was brighter than the other. The disappearance of the cursor on the computer screen was a trigger for several people

And it's a miracle my mouse managed to survive! I kept bashing the stupid mouse—I don't think it ever occurred to me it was me! (G2)

Even those who had noticed specific problems with their vision recalled that the actual label of 'glaucoma' was an unexpected one. For some, a history of 'normal' poor eyesight had framed such problems as everyday or unthreatening ones, so it was the potential seriousness of glaucoma that was surprise

The entire family, all of us, my mummy, everybody wear glasses. And so, nobody took it seriously, just how bad it was. (G1)

I suppose it was a coincidental diagnosis ... I just went along for my normal six monthly contact lens check ... and the doctor decided to check my pressures, and I just thought 'he can't find anything, surely?' ... so I went back in December, the diagnosis was confirmed: yes, she has bilateral glaucoma. (G1)

To some extent, glaucoma was a 'surprise' because it did not fit with respondents' reported concepts of sight disability. Many knew little about glaucoma prior to diagnosis. The domain of 'eyesight problems' fell into two categories; the unremarkable, mundane problems of poor vision corrected by spectacles or contact lenses, and 'blindness', considered by many respondents to be a disability one either had or did not have. The concept of a potentially serious disease that might gradually cause sight loss did not fit with pre-existing ideas about eye health

[The diagnosis] put me down, depressed me terribly. I'd never considered it you see. I'd heard of glaucoma, but I didn't know, for instance, it could creep up on you without you realising. 'Cause it's, it's so silent, so without warning it strikes, doesn't it? (I6)

I'd never heard of glaucoma—always thought vision [was an] open/shut affair. (I2)

This lack of awareness of the gradual effects of glaucoma reflected general perceptions of 'blindness' and what it meant to be blind. Few respondents identified themselves as blind or partially sighted, and those with some functional sight referred to people with partial sight or blindness in terms of having no vision at all. Concepts of what blindness meant were based largely on others: individuals they had known or known about. Images of 'blind people' fell overwhelmingly into two categories. The first were of victims—a mix of sympathy or pity for the extreme dependence that was seen to result from blindness

When I was about four, I used to run into the house of a man next door... and that man was completely blind. His wife got him up, I suppose, dressed and changed him. He sat there all day long. He never went out. (I2)

I fear for them [blind people], quite frankly. I see them going along the road, and I'm afraid for them. (I6)

The other set of images were heroic, and admiring of achievements in the face of disability

And he used to sing solo, in concerts, and he read the words with his left hand, and the music with his right, in Braille. Which is pretty awe-inspiring, I think. (I1)

How David Blunkett manages to be Secretary of State for Education, I'll never know. Absolutely amazing, without being able to see. (I8)

In general, the images of blindness referred to by respondents were, then, of others rather than the self, and were either unappealing or unachievable as models to aspire to. One exception was a man with diabetes, who recalled being surprised by field test results at the time of the diagnosis, but saw the diagnosis as, in retrospect, predictable, as eye disease was a perceived risk. This participant reported less extreme perceptions of what blindness might mean, and an image more rooted in a social model of disability

I've listened for years to the talk on the radio programme for blind and partially sighted people ... it's a good programme... This programme helped, because many people are living quite normal lives. (I5)

Given the low reported level of awareness of glaucoma, and of the range of eye problems expected by most respondents as part of 'normal life', few of those interviewed reported that particular symptoms were a trigger for their decision to seek professional help. The exceptions were those with occupations which demanded attention to eyesight. At the individual level, the key 'barrier' to early referral was, then, accommodation to and normalising of sight loss. Problems with eyesight—prior to diagnosis—were not identified as 'disabling'. Only after diagnosis could apparently mundane disabilities be re-framed as potentially serious and threatening 'symptoms'.

The impact on everyday life

Given that many participants had coped, perhaps subconsciously, with diminishing visual ability before their diagnosis, most had found a variety of ways of minimising the impact of symptoms on everyday life post-diagnosis. These included double checking the position of objects (such as cups before pouring water), making sure kitchen implements or tools were always left in the same position, and improving household lighting. Of course such strategies are to some extent the actions many people without glaucoma take to reduce clumsiness, or cope with the 'normal' bodily deterioration of advancing age, so were not in themselves evidence that 'something unusual was happening' pre-diagnosis. Once their eyesight difficulties had been labelled specifically as 'glaucoma', participants could

be more explicit about these as ‘coping strategies’, rather than merely carefulness or tidiness. In the focus groups particularly, participants discussed the techniques they had developed to manage everyday tasks

R1 A real classic is when you drop something, and it just goes bouncing off, and then its down on the floor, sort of scanning—you have to learn to scan

R2 That’s it, scanning—

R1 Like a radar, sort of

R2 Yeah, like a robocop! (G2)

Participants in the two focus groups also shared tips with each other for how to cope with glare from lighting and reductions in visual fields, such as writing with thick felt pens; wearing hats outdoors to reduce the lighting difference between in- and outside and investigating the possibility of voice-recognition software for computers. In hearing other peoples’ accounts of symptoms, some participants re-labelled experiences specifically as the effects of glaucoma during the focus group itself

I’m wondering, listening to you, because I have a job to recognise textures ... and I couldn’t see details like where buttons were on garments ... so maybe that’s the glaucoma. (G2)

However, despite the sense in which such experiences were shared, the individual impact of sight loss was of course variable, and contingent on particular circumstances. Social roles, occupational roles, family support and physical environment all shaped whether, or the extent to which, glaucoma symptoms led to disability. The potential impact on work was predictably a concern for many below retirement age. One man, a painter, summed up perhaps the psychological as well as financial importance of work to self-identity

I would try to go on [if eyesight deteriorated]. As long as I could I imagine... because after that it’s almost unthinkable, isn’t it, really. You know, when you’re not earning any more, it means nobody’s wanting you any more, it means you’re not of service anymore. (I4)

For participants of all ages, two aspects of daily living were commonly reported as having the most significant impact on lifestyle—decreasing ability to drive and read. Problems with reading, for many, were the greatest hardship, and several talked about fears of being no longer able to read

I can’t tell you how important reading is to me. And as I get older, it gets more important. [If it deteriorated] I wouldn’t care about living any more, to be honest with you. (I6)

For me, being so young, it’s really difficult, because I used to read a lot. Now I’m limited, I just have to read for an hour, two hours a day and I miss that a lot, because I love reading. (G1)

This quote illustrates the importance of occupational context. For this young woman, limiting reading to two hours a day was a restriction, as she was studying for a degree, so there was no additional time available to read for pleasure. Clearly, for those in different circumstances, being able to read for only one or two hours a day might not at all be disabling.

The loss of ability to drive was similarly reported as a significant disability for many. Several participants reported that they had tried to hold on to their driving licences for as long as possible, using a variety of strategies to reduce the chance of vision problems causing an accident. These included avoiding driving during darkness, not using underground car parks, or only driving routes they knew well. However, for some, the loss of a licence had not been as devastating as they had predicted

Losing your driving licence—that is the pits. I thought that was the worst thing that could happen to me—it’s not, as I’ve discovered. (G2)

Again, the quality of the external environment shaped the experience of loss. One man described his regret at losing his car, but went on to comment that being unable to drive would be less of burden ‘if public transport was to run on time’ (I11). For a largely urban sample, with access (if limited) to public transport, using a car (or the legitimate right to) may have more symbolic than practical importance, as a marker of independence.

For most participants, it was the apparently minor activities of daily living that were the focus of their accounts of the impact of glaucoma on their lives. These included particular losses which were keenly felt, such as an inability to eat fish as the bones could not be seen, or to play tennis. Clearly, the salience of difficulties was rooted in their particular social circumstances. For some, the realisation that the everyday tasks they could once manage with ease were now difficult and uncertain was reported as having a significant impact on self-image. For women, particularly, managing the home and childcare with efficiency was compromised, which could have disturbing implications for feelings of self worth. One woman described an incident that struck her as a ‘defining moment’ in the course of her coming to terms with the implications of glaucoma

I came back [from the supermarket] with what I thought was potatoes, and they were onions. (G1)

Thus, an apparently mundane, everyday mistake takes on a particular significance in the context of maintaining a valued social role into the future. Similarly, many

participants talked about the problems of seeing ground level activity, and therefore accidentally kicking household pets, or bumping into small children, but for one woman, this was the ‘worst thing’ about living with glaucoma

That’s the worst thing, I was always bumping into my children and I was always losing my children, you know I’d be walking, and I’d say ‘where’s Rosie?’ and Rosie, well she was right beside me! (G1)

For women, especially, the need to involve male partners in tasks formerly considered ‘their work’ was difficult and potentially guilt inducing

And he’s very tired at the weekend, so it’s very difficult. I will go to the supermarket, but he has to come and collect me. But em, it is an extra sort of burden. (G1)

Other participants reported that diminishing visual ability had not had serious impact on their quality of life, despite meaning that driving was no longer possible, and gardening and other household tasks were more difficult. One man, having described how glaucoma had stopped him driving and thus travelling to see his family or going for days out in the country, said he was not worried about the long term implications of being ‘dependent’

Knowing my wife, I mean I’ve got no worries in terms of what she would do for us in any case ... I wouldn’t have any problems ... [I’d] be looked after. (I2)

In general, the men in the sample were less likely to express fears about their dependence on partners and other family members

I rely very much on my wife, who knows that in a strange environment I cannot walk quickly and she’ll walk in front of me. (G2)

In a focus group, one young woman, a student from a large family, described similar routine expectations she had of help in getting to college from kin. However, others in the group pointed out that this was a solution not open to many in the relatively more isolated families typical of English cities

R1 My sisters and aunts help, when anybody has time

R2 So you’re really dependant on your family or friends ... well my mother and father have now died, and there’s no one, my sisters are [abroad] I can’t suddenly ring up and say ‘well can you just help me get to the supermarket!’ (G1)

The meaning of independence was, then, rooted not in ‘visual ability’ but in social roles and relationships.

However, most participants did talk about strategies used to preserve both independent mobility and manage day to day activities at a practical level. Accounts of everyday life thus stressed that one ‘coped’—but often at a cost.

‘Coping at a cost’

The notion of ‘coping at a cost’ characterised the ways in which the demands of various roles (family, work, leisure) were balanced. Therapeutic interventions (including drug treatments and surgery) to preserve sight were not unequivocal benefits, but also ‘risks’ which had to be accounted for in the equations of coping. Eye drops, for instance, often had side effects, including temporary blurred vision, which generated their own challenges for managing the working day

You were sort of handicapped for an hour after each time you put the drops in, because everything went dark. (I7)

For those still working, this meant that they might have to get up an hour earlier than usual to make sure their eyesight had returned to normal in time for the working day. Some participants coped by reducing the tasks they did at work

There are some things I probably now won’t do, professionally—I used to give quite a lot of talks, and I’m not going to do that—the idea of going on to platforms ... would it be a day I couldn’t see my notes? (G1)

Others reported maintaining working roles, but at a cost to other areas of their life, such as family time or leisure activities, because of fatigue. However, for most of those still working there were significant concerns about the future impact of sight loss on their ability to do their job, or to cope with the workloads expected

Before I used to work, you know, I could be in the office till about 8 o’clock, but I don’t do that no more... and that may be another thing my boss ain’t happy about, because I’m not putting in the hours. (I11)

The other aspect of ‘coping at a cost’ is the balance to be maintained between the practical issues of mobility while projecting an image of an independent self. People with severe glaucoma may not present to the outside world as ‘disabled’, in that there may be no visible signs of impairment. In Goffman’s (1963) phrase the stigma is ‘discreditable’ rather than ‘discredited’, and many participants in this study valued being able to present as ‘normal’, rather than sight impaired, or blind. However, this of course brings practical problems when routine expectations of ability (that you will see small

children in a crowded train station, or the floor buttons in a dim lift) are not met. In the focus group discussions particularly, participants talked about these tensions between wanting to present as 'normal' and managing with tasks such as mobility

R1 People say you look normal

R2 yes, you don't necessarily look it yourself, but you look normal (laughter)

R1 And when its good you actually feel—

R1 Yeah

R2 Relatively normal. And so you think, I can do it

R1 Yeah, Yeah

R2 And you can act normal (G1)

Going somewhere really dark, I sort of get panicky, in case I don't see something or someone and walk into them, 'cause they don't know what you're suffering with and I don't want to sit down and have to explain to someone what's wrong with me. (I9)

Deciding whether, and how to, use a 'white stick' was a key example for many. Although there were recognised advantages (that it enabled you to gauge the depth of steps, and drew attention to ground level hazards that may not be within eyesight), it also added new challenges to any task. Some were practical—a stick is one more thing to carry from the shops, for instance, as shopping has to be done on foot. Others were interpersonal—using a white stick meant the possibility of unwanted attention from others. The white stick is a very potent symbol of disability, and rejected by many. One solution to the dilemma was to carry the stick, in case it was needed—but not visibly

I've got a white stick—in my handbag! When I use it, I have enough vision that I can see people looking at you quite openly ... and then people offer you seats on the bus or whatever, you get a little bit more attention, so I get embarrassed. (G1)

Similarly, walking with a guide could lead to feelings of stigma

When I usually walk with my sister, people think that I don't see anything at all, and you know, they'll start staring at me, I feel uncomfortable. (G1)

This example reflected the lack of understanding about the effects of glaucoma that some participants felt was a problem. Just as they had not understood much about the disease pre-diagnosis, they noted that the misconceptions of acquaintances could present problems. One man talked about a tennis partner who slowed down the game, although this actually made the ball harder to see.

Others talked about the way in which friends would point out the easily seen sights (a mountain, trees in the distance) but not the hazards out of their field of vision, such as unexpected steps, kerbs or street furniture. Even professional helpers could lack understanding of the impact of glaucoma

After six months on the waiting list I had a rehabilitation worker ... she said 'what is the problem with your eyes?' I mean this was because I was registered blind, and I just said 'oh its glaucoma' and I nearly dropped dead when she made the next comment—'Oh, is that all?' (G1)

For many participants in this study, then, the impact of glaucoma symptoms on everyday life could be managed—but at a potential cost. Such costs included practical constraints on carrying out work and family roles, and interpersonal constraints in managing interaction in a world with routine expectations of sight ability.

Discussion

This study found few triggers to early referral for diagnosis. Symptoms identified in retrospect, such as blurred vision in the morning, or haloes around lights, may be indicative of corneal oedema, but were not interpreted as meaningful symptoms until after diagnosis. People accommodated to deteriorating sight well, and explained symptoms in terms of everyday eye sight problems that are seen to be the inevitable result of ageing, or 'normal' clumsiness. In a society in which a large proportion of the population has corrected vision, minor eyesight problems are seen as 'normal problems', easily accommodated until it becomes obvious that 'something unusual is happening'. Clinically, visual function is assessed in a number of ways, including acuity, contrast sensitivity, colour perception and field of vision. For most of the population, visual acuity is the key aspect of eyesight that impacts on awareness of 'visual ability', and diseases (such as glaucoma) in which other functions are affected without loss of acuity are unlikely to prompt self-referral until late in the disease process.

Given that there are often no specific triggers, except for those reliant on excellent vision for work, the diagnosis of glaucoma is usually made as a result of findings from routine eye sight tests, rather than as a result of patients seeking professional help for specific symptoms. The participants in this study, who were almost all 'surprised' by the diagnosis of glaucoma, reported a lack of understanding of the disease pre-diagnosis that may reflect that of the wider population. This was echoed in their accounts of discussing their condition with friends, acquaintances and even profes-

sional workers post-diagnosis. Many were faced with perceptions that glaucoma was exclusively a disease of old age, or that it was a minor condition which would not cause disability.

Once diagnosed, and labelled as 'glaucoma patients', everyday experiences of sight problems could be re-framed in retrospect as symptoms and fateful portends of potential future disability. Diagnosis thus does more than provide access to medical treatment—it also shapes the way in which sight loss is experienced and accounted for. The 'biological disruption' (Bury, 1982) of an unexpected diagnosis had to be reintegrated within the stories participants told of their current strategies for coping and their concerns about the future. These stories underlined a social model of disability, in which the key factors were not the extent of clinical impairment (which was reported as a poor guide to lived experience), but the social and physical environment. 'Coping' was essentially a social phenomena—rooted for example in the extent to which partners and wider kin saw it as a routine part of family obligations to help with mobility, and the value placed by participants themselves on independent mobility. 'Independence' clearly had different meanings depending on gender, age and other social factors. For the younger women, particularly, in this study decreasing independence (to shop, look after the children and work) was reported as keenly felt disability. For some other participants (particularly the older men, and one young woman who lived with her extended family), there were routine expectations that others (wives, relatives) would help as an extension of their normal roles, and the lack of independent mobility was consequently not reported as disabling. That adaptations to coping are gendered has been noted in other contexts (see, for instance, Robinson (1988) on the impact of multiple sclerosis). The meaning of independence is also rooted in wider cultural values. Charmaz (1983), in her study of the impact of chronic illness on self-identity, noted that 'residuals of the Protestant Ethic' pervaded the notion of a valued self for the participants in her North American study. Hard work and independence were the essence of self worth, and those with chronic illness faced a double burden of the impacts of disease and a diminished sense of self. Some participants in this study made reference to similar ideas, with working (both paid and unpaid) roles clearly crucial to a sense of self.

In most communities in societies such as the United States and Britain, independent mobility is a highly prized attribute, with cultural value being placed on one's ability to manage everyday activities, earn a living and maintain social relationships without aid. The achievement of such 'independence' is assumed to be key characteristic of healthy adulthood and a desirable ideal, though many have criticised an unproblematic assumption that people with disabilities wish for

independence (French, 1993). 'Independence' is too easily equated with 'doing everything for yourself', and measures of ability focused on whether someone can bathe themselves, dress themselves or move unaided. Given the high levels of inter-dependence in modern societies (Keindal, 1999), the notion that any member of a community is 'independent' in this sense is of course a nonsense—few could provide themselves with food, shelter and self care without help from both other people and technological aids. As Brisenden (1998) points out, independence is more usefully conceptualised not as 'doing everything for yourself' but rather as the amount of control over everyday routines. Clearly this control is socially distributed (by, for instance, age and gender) independently of any health-related disability, and the impact of symptoms is highly contingent on the specific social circumstances. The very concept of 'independence' is constructed differently depending on point in the life cycle, gender and kinship networks. In sum, the key to whether people with moderate to severe glaucoma were 'disabled' by sight loss was not clinical impairment (many participants noted the difference between their subjective assessment of their ability and clinical findings) but social and physical environments.

Although most participants were positive about the treatment they received from their hospital specialists, they were less positive about help they had received from rehabilitation services, such as those offered to help people use white sticks or consider household aids. That the focus groups in this study were used to discuss strategies for coping, and to exchange ideas for managing symptoms and treatment regimes, suggests that there is as much a need for this kind of mutual support as clinical treatment. In 1967, Scott wrote of provision of services for blind people in the USA that 'clients' needs and the kinds of available welfare services run in two separate orbits, which coincide only at certain points' (Scott, 1967, 249). It appears that this is still, to an extent, true of the UK over thirty years later. Despite advances in clinical treatment, there are few advances in providing practical help for those disabled by an environment designed almost exclusively for the sighted.

Scott also wrote about the role of experts in turning those who don't see well into 'blind men' (Scott, 1970). Again, there are echoes of this finding in the present study. Pre-diagnosis, participants reported 'normal' problems of vision; post-diagnosis, they had fateful symptoms of a chronic disease labelled 'glaucoma'. However, few accepted the labels 'blind' or 'partially sighted' offered by 'experts'. For many of the participants in this study who still had some functional vision, images of 'blindness' were negative ones, resonating with broader social stereotypes of blindness—that the only roles open were 'victim' or 'hero'. Glaucoma, because its onset is insidious, can involve those diagnosed in a long (often permanent) transition between the taken for

granted role of 'sighted' and the problematic role of 'blind'. Some participants resisted registering as blind, or displaying themselves as blind people by using a white stick in public. Thus, a potential key to independence is in itself perceived as stigmatising rather than enabling. Despite resisting the stigmatised label, many nevertheless reported significant current disabilities, concerns about future prognosis, and social difficulties arising from the routine expectation that they had 'normal' eyesight. To some extent, this reflects the impoverished models of blindness available—few can be heroes, and few wish to be victims. Instead, many adopted a strategy of 'coping at a cost': maintaining a valued self-image of 'normally sighted person' (within that large range in a population where many have corrected vision), while developing practical and social strategies to maintain physical mobility and social roles.

Glaucoma presents particular problems in terms of raising awareness for case finding. Symptoms are typical of problems that are 'normal' results of tiredness, minor eyesight problems or ageing and they are thus easily accommodated. Few of the participants in this study had pre-existing ideas of what glaucoma was, and many noted that they and the wider public saw it as 'tunnel vision', or sudden blindness, and as being exclusively associated with old age. By the time people have noted that 'something unusual is happening' their eyes may be already damaged. Health promotion information is usually only found in eye clinic waiting rooms, where the population is already well informed. There is some evidence from other countries that appropriate health promotion may increase numbers presenting for case finding. Previous studies from Australia, for instance, suggested that those who are more aware of eye disease accessed services more frequently (Attebo, Mitchell, Cumming, & Smith, 1997, Livingstone et al., 1995). However, there are distinct disadvantages to mass screening for a disease that is difficult to detect without careful examination and interpretation of test results. This suggests that the key to reducing the impact of glaucoma in the community may be improved information aimed both at those groups at high risk and at their primary care providers, and reduction of any barriers to case finding (such as costs of eye tests) in those groups.

To reintegrate the social model of disability, such attention to the 'barriers to diagnosis' must be done in conjunction with a reduction in the cultural, social and political barriers to the social participation of those with sight loss. Such barriers not only impact on those who have sight loss from glaucoma, but also frame public understanding of what sight disability and blindness is. This study has suggested that cultural frameworks which stereotype sight loss as either mundane and trivial or as devastating 'blindness'

are, first, barriers to initial self referral for vision problems, as diseases like glaucoma do not fit either model. Second, they act as potential barriers to accessing appropriate services for those with sight loss, as accepting registration as blind or partially sighted may be equated with accepting a de-valued 'blind' identity.

Conclusion

Glaucoma is a leading cause of preventable vision loss. Participants in this study reported low levels of awareness of glaucoma pre-diagnosis. After diagnosis, problems with vision were re-framed as 'glaucoma symptoms' to be coped with in managing everyday life. Problems faced were related more to social and environmental contexts than to clinical symptoms. A broad campaign to raise awareness of both glaucoma and the possibility of management within high-risk groups might increase the number of patients identified before the disease has progressed. This needs to be done in the context of awareness of the ways in which modern urban environments, in particular, discriminate against those with sight loss. Second, attention must be paid to how cultural frameworks, such as categories of sight disability, contribute to both the social exclusion of people with sight loss and the barriers to self-referral.

Acknowledgements

This study was funded by the Moorfields Eye Hospital Special Trustees. We are grateful to the participants in this study, who gave their time very generously. We would also like to acknowledge the help of Sally French, Nicki Thorogood and an anonymous referee who commented on an earlier draft.

References

- Ainlay, S. C. (1989). *Day brought back my night: Ageing and vision loss*. London: Routledge.
- Attebo, K., Mitchell, P., Cumming, R., & Smith, W. (1997). Knowledge and beliefs about common eye diseases. *Australian and New Zealand Journal of Ophthalmology*, 25, 283–287.
- Barnes, C. (1998). The social model of disability: A sociological phenomenon ignored by sociologists? In T. Shakespeare (Ed.), *The disability reader: Social science perspectives*. London: Cassell.
- Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: A sociological introduction*. Cambridge: Polity Press.

- Bell, R. W. D., & O'Brien, C. (1997). The diagnostic outcome of new glaucoma referrals. *Ophthalmic and Physiological Optics*, 17, 3–6.
- Bickenbach, J. E., Chatterji, S., Radley, E. M., & Üstün, T. B. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science and Medicine*, 48, 1173–1187.
- Brisenden, S. (1998). Independent living and the medical model of disability. In T. Shakespeare (Ed.), *The Disability Reader: social science perspectives*. London: Cassell.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4, 167–182.
- Bury, M. (2000). A comment on the ICDH2. *Disability and Society*, 15, 1073–1077.
- Charmaz, C. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, 168–195.
- Coffey, M., Reidy, A., & Wormald, R., et al. (1993). Prevalence of glaucoma in the West of Ireland. *British Journal of Ophthalmology*, 77, 17–21.
- French, S. (1993). Whats so great about independence? In J. Swain, V. Finklestein, S. French, & M. Oliver (Eds.), *Disabling barriers—enabling environments*. London: Sage/Open University Press.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Harmondsworth: Penguin.
- Jay, J. L., & Murdoch, J. R. (1993). The rate of visual field loss in primary open angle glaucoma. *British Journal of Ophthalmology*, 77, 176–178.
- Keindal, S. M. (1999). Independence, dependence and interdependence: Some reflections on the subject and personal autonomy. *Disability and Society*, 14, 353–367.
- Landes, R., & Popay, J. (1993). My sight is poor, but Im getting on now The health and social care needs of older people with visual problems. *Health and Social Care in the Community*, 1, 325–335.
- Livingstone, P. M., Lee, S. E., De Paola, C., Carson, C. A., Guest, C. S., & Taylor, H. R. (1995). Knowledge of glaucoma, and its relationship to self-care practices, in a population sample. *Australian and New Zealand Journal of Ophthalmology*, 23, 37–41.
- Mitchell, P., Smith, W., Attebo, K., & Healey, P. T. (1996). Prevalence of open angle glaucoma in Australia: The blue mountains study. *Ophthalmology*, 103, 1661–1669.
- Nelson, P., Aspinall, P., & O'Brien, C. (1998). Patients perception of visual impairment in glaucoma: A pilot study. *British Journal of Ophthalmology*, 83, 546–552.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. Basingstoke: Macmillan.
- Pfeiffer, D. (2000). The devils are in the details: The ICDH2 and the disability movement. *Disability and Society*, 15, 1079–1082.
- Quigley, H. A. (1996). Number of people with glaucoma worldwide. *British Journal of Ophthalmology*, 80, 389–393.
- Robinson, I. (1988). Reconstructing lives: Negotiating the meaning of multiple sclerosis. In R. Anderson, & M. Bury (Eds.), *Living with chronic illness: The experiences of patients and their families*. London: Routledge.
- RNIB (Royal National Institute for the Blind), 2000. <http://www.rnib.org.uk/wesupply/fctsheets/authuk.htm>
- Scott, R. A. (1967). The selection of clients by social welfare agencies: The case of the blind. *Social Problems*, 14, 248–257.
- Scott, R. A. (1970). The construction of conceptions of stigma by professional experts. In J. D. Douglas (Ed.), *Deviance and respectability: The social construction of moral meaning*. New York: Basic Books.
- Shakespeare, T., & Watson, N. (1997). Defending the social model. *Disability and Society*, 12, 293–300.
- Sommer, A., Tielsch, J., & Katz, J., et al. (1991). Racial differences in the cause specific prevalence of blindness in East Baltimore. *New England Journal of Medicine*, 325, 1412–1417.
- Strauss, A. (1987). *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.
- WHO (World Health Organization), 1980. International Classification of Impairments, Disabilities and Handicaps. Geneva: WHO.
- WHO (World Health Organization), 2000. ICDH-2: International Classification of Functioning, Disability and Health (Pre-final draft). Geneva: WHO.



Can a public health package on glaucoma reach its target population?

H Baker¹ and IE Murdoch^{1,2}

Abstract

Purpose A pilot study to assess how successful a newspaper advertisement and a radio interview about glaucoma are at reaching their target population.

Methods The health intervention comprised two components: an interview on local radio and an advertisement in the local paper. Our target population were residents aged 45 years and above in either Southall (West London) or the Isle of Wight (IOW). A questionnaire was developed to be carried out pre- and post-intervention. The data from both locations pre and post were coded and cleaned. Tests of significance were carried out to assess statistical significance for differences in proportion, with tests for trend used where appropriate. All statistical analyses were carried out using Stata7.

Results Overall, the proportion who had heard of glaucoma increased from 54% before the intervention to 60% after ($\chi^2 = 3.7$, $P = 0.055$). The proportion who had heard of the disease increased by 13% ($\chi^2 = 8.76$, $P = 0.003$) in Southall and by 8% ($\chi^2 = 5.02$, $P = 0.025$) on the IOW. The proportion reporting seeing the advert increased significantly in both areas with greater effect in Southall. Those reporting hearing the radio interview only increased in Southall. On the IOW, females were more knowledgeable and responded more positively to the intervention. This differed in Southall where males tended to be the positive responders.

Conclusion In both areas a significant effect on those having heard of glaucoma was found. This could be attributed to both the advert and interview in Southall but would appear to be attributable to the newspaper advertisement alone on the IOW.

Eye (2004) 18, 478–482. doi:10.1038/sj.eye.6700688

Keywords: glaucoma; public health package; target population

Introduction

Primary open-angle glaucoma affects 1–2% of people over 40 years of age in Caucasian and Indian populations.^{1–4} The disease is strongly age related and results in a progressive, irreversible loss of the field of vision. It is largely asymptomatic until the late stages and is the major cause of preventable blindness in the elderly in the United Kingdom.

In the developed world, only 50% of those with the disease are diagnosed and receiving therapy.^{5–8} The reasons for this have been the subject of a programme of research by our group. We are approaching the problem from two directions; disease detection within the community, and public health-seeking behaviour. This study relates to the latter aspect.

Mass media is often used as an element of social marketing campaigns and is particularly of value where issues are seen to be of relevance to large proportions of the population. It has been observed that with any campaign it is likely that a proportion of the target group will not be exposed to the campaign, and a further proportion will not recall, understand or act on the message.⁹ Despite this, mass media remains one of the few options available for the communication of issues to large numbers of people. Research and evaluation of the use of mass media in health promotion has shown that it can be used effectively within certain areas.¹⁰ It can raise consciousness about health issues, convey simple information, and change behaviour.

This project is part of a larger intervention study. The main study aims to implement a health promotion campaign for glaucoma and to assess its impact on health knowledge and health-seeking behaviour. This paper reports on a pilot study used to assess how successful a newspaper advertisement and a radio interview about glaucoma can be at reaching their target population.

¹Department of Epidemiology and International Eye Health Institute of Ophthalmology London, UK

²Moorfields Eye Hospital City Road London, UK

Correspondence: H Baker
Department of Epidemiology and International Eye Health Institute of Ophthalmology 11-43 Bath Street London EC1V 9EL, UK
Tel: +44 20 7608 6896
Fax: +44 20 7250 3207
E-mail: h.baker@ucl.ac.uk

Received: 15 May 2003
Accepted: 15 July 2003

Methods

Study location

Two very different populations were chosen for the study: the IOW and Southall (West London). Both were good for such a study because they had single radio stations for the community, local press and an established community network. The IOW is a mainly Caucasian population with an age bias towards the elderly. Southall, is a multicultural, diverse urban population with a substantial number of Indian origin.

The campaign

The health intervention comprised two components: an interview on local radio and an advertisement in the local paper. Our target population was people aged 45 years and above who were residents in either Southall (West London) or the IOW.

Campaign resources were developed to promote the campaign message to our specific target group (Table 1). The advertisements emphasised the importance of glaucoma and whom to contact for further information.

Interview on local radio

We decided that, for the purpose of this study, an interview on the radio would be more suitable than a radio 'phone in'. The interview was trailed for 3 days prior to its taking place. These trailers also contained information about glaucoma.

Questionnaire

A questionnaire was developed to be carried out pre- and post-intervention. The baseline questionnaire was used to establish the proportion of individuals who were positive responders in the absence of a true campaign. The questionnaire was then carried out after the intervention to establish the impact of the campaign. The

questionnaire was administered in English on the IOW and Hindi in Southall. In the latter location the advertisement and interview were in Hindi so it was vital to carry out the questionnaire in the same language.

Sampling

A convenience method of sampling was used in each area. People were approached in the High Street and in local temples in Southall and in the main town centre in Newport, IOW. People had to be within the correct age range and a local resident to be included in the study. Our sampling method has limitations as people who were housebound or did not frequent the areas of sampling would be excluded from the study.

Data analysis

The data from both locations pre- and post-intervention were coded and cleaned. Tests of significance were carried out to assess statistical significance for differences in proportion and logistic regression undertaken to assess confounding. All statistical analyses were carried out using Stata7.

Results

In total, 1104 records were included in the analysis. Characteristics are shown in Table 2.

Overall the proportion who had heard of glaucoma increased from 54% before the advert and interview to 60% after ($\chi^2 = 3.7$, $P = 0.055$). There was a large difference between areas. In Southall, about one-quarter (27% (95% CI, 21–33%)) of people had heard of glaucoma prior to the intervention whereas about three-quarters (75% (95% CI, 72–79%)) had heard of glaucoma on the IOW. The proportion who had heard of the disease increased by 13% in Southall and 8% on the IOW after the interventions. The proportion reporting seeing the advert increased significantly in both areas with a greater effect

Table 1 Advertisement Design Access.

Procedure

- Review previous and current glaucoma advertisements
- Brainstorm and design six prototype adverts
- Discuss adverts with eye health specialists—glaucoma doctors, nurses, optometrists and orthoptists
- Redesign adverts
- Discuss adverts with glaucoma patients to ensure they did not offend or cause anxiety to people with glaucoma
- Narrow adverts down to three

Southall

- Translate adverts in to Hindi
- Carry out focus groups with target population in Southall
- Choose advert for Southall

Isle of Wight

- Individual discussions with IOW residents from our target population.
- Choose advert for IOW

**Table 2** Sample Demographics.

	Southall		Isle of Wight	
	Pre N = 190	Post N = 298	Pre N = 304	Post N = 312
<i>Age group (years)</i>				
46–55	24 (13%)	16 (5%)	83 (27%)	75 (24%)
56–65	48 (25%)	41 (14%)	79 (26%)	90 (29%)
66–75	74 (39%)	146 (49%)	89 (29%)	99 (32%)
76–85	33 (17%)	78 (26%)	44 (14%)	42 (13%)
86 +	11 (6%)	17 (6%)	9 (3%)	6 (2%)
<i>Gender</i>				
Male	99 (52%)	153 (51%)	121 (40%)	121 (39%)
Female	91 (48%)	145 (49%)	183 (60%)	191 (61%)
<i>Ethnicity</i>				
Caucasian	0	0	100 (100%)	100 (100%)
Indian	170 (89%)	290 (97%)	0	0
African	19 (10%)	8 (3%)	0	0
Other	1 (1%)	0	0	0

Table 3 Percentage of sample who had heard of glaucoma or seen intervention.

	Southall N (%)		Isle of Wight N (%)	
	Preintervention	Postintervention	Preintervention	Postintervention
Not heard of glaucoma	139 (73%)	179 (60%)	87 (29%)	65 (21%)
Heard of glaucoma	51 (27%)	119 (40%)	217 (71%)	247 (79%)
	$\chi^2 = 8.76, P = 0.003$		$\chi^2 = 5.02, P = 0.025$	
Not seen advert	183 (96%)	217 (73%)	277 (91%)	257 (82%)
Seen advert	7 (4%)	81 (27%)	27 (9%)	55 (18%)
	$\chi^2 = 43.34, P = 0.000$		$\chi^2 = 10.21, P = 0.001$	
Not heard interview	177 (94%)	238 (80%)	297 (98%)	302 (97%)
Heard interview	11 (6%)	60 (20%)	7 (2%)	10 (3%)
	$\chi^2 = 18.85, P = 0.000$		$\chi^2 = 0.47, P = 0.49$	

in Southall, while those reporting hearing the interview on radio only increased in Southall (Table 3).

There was a difference between male and females: in Southall more males than females reported having heard of glaucoma. Prior to the intervention this was not significant (females 24%, males 29%, $\chi^2 = 0.63, P = 0.43$), however, it reached significance after the intervention. (females 33%, males 46%, $\chi^2 = 5.49, P = 0.02$). On the IOW, the opposite was the case: before the intervention more females than males reported having heard of glaucoma (females 76%, males 64%, $\chi^2 = 4.71, P = 0.03$). After the intervention this difference was even greater (females 85%, males 69%, $\chi^2 = 11.4, P = 0.001$).

In both areas there was a small tendency for the younger age groups to report having heard of glaucoma more frequently.

The sources of knowledge for having heard of glaucoma differed between areas. Most on the IOW either could not remember where they had heard of the disease or had a friend or relative with the disease. There was more of a spread of information sources in Southall, TV or general knowledge being given as the most common source of knowledge. In both areas there was an effect in the proportion reporting having recently been exposed to knowledge of the disease following the intervention. This was, however, very large in Southall and small on the IOW.

There was no pattern to those who reported having heard of glaucoma by occupation in Southall, either before or after the intervention. On the IOW all grades of occupation had similar proportions who reported having heard of glaucoma. After the intervention there was a

selective increase in those reporting having heard of glaucoma, the professional group showing a striking effect (62% before and 92% after), with only a suggestion of effect in the retired group and no clear effect in any other group.

Logistic regression was undertaken with 'heard of glaucoma' as the outcome. Crude odds ratios showed a significant effect for the intervention: IOW (OR 1.52 (1.05–2.20, $P=0.03$)), and Southall (OR 1.81 (1.22–2.69, $P=0.003$)). A younger age was associated with having heard of glaucoma on the IOW ($P=0.001$) but not significantly in Southall ($P=0.11$). On the IOW, females were more likely to have heard of glaucoma (OR 0.48 (0.33–0.70, $P=0.000$)). In Southall, males were more likely to have heard of glaucoma (OR 1.56 (1.07–2.27, $P=0.02$)).

In a complete model adjusting for age, gender, and intervention the only important factor was the intervention (IOW predicts perfectly, Southall OR 1.60 (0.96–2.65, $P=0.07$)).

Discussion

In Southall, there was a significant impact with a higher proportion of individuals reporting seeing the advert, hearing the interview and having heard of glaucoma after the intervention. On the IOW the same findings occurred for the advert and having heard of glaucoma but there was no clear effect in terms of those reporting hearing the radio interview.

There were striking differences between the two populations. Not only was the ethnic composition different, as anticipated, but many more people at baseline had heard of glaucoma in the IOW: 71% compared to 27% in Southall. This could be due to social deprivation. Fraser *et al*¹¹ carried out a case-control study into risk factors for late presentation in chronic glaucoma and found social deprivation to be a major risk factor. This may be influenced by level of education. When we look at ward data from Ealing Council, 40% have poor literacy and 41% to have poor numeracy in Southall¹² well above the UK average. The variation could also be a result of ethnic differences. Patel and Murdoch have shown that Indians do not see health as the highest priority.¹³

More females on the IOW reported having heard of glaucoma. This result could be due to females accessing health care more than males.¹⁴ An interesting observation is that in Southall it was reversed; more males than females reported having heard of glaucoma.

Positive responders in Southall varied between 4 and 7% and on the IOW 2–9% for having heard adverts or interviews that had not yet taken place. This is in keeping with previous work.¹⁵ If an average of 5% positive

responders is subtracted from the results post-intervention 22% saw the advert in Southall, and 13% saw the advert on the IOW. In Southall 15% heard the interview while there was no clear effect of the interview on the IOW.

Only Southall showed an effect with the radio interview with an increase of 13%. Preliminary work in both areas prior to the interview showed everyone reported listening to Sunrise Radio in Southall while only 50% in the IOW reported listening to local radio. This would allow for a smaller effect in the IOW than in Southall but for it to have no effect there must have been other contributing factors. The interview could have been placed at the wrong time of day for our target population although we did try to get around this by having the adverts leading up to the interview throughout the day. On the day of the interview on the IOW, glaucoma was also featured as an item in their 6am and 6pm news programme. This, however, was not mentioned by any of the interviewees. In contrast, Southall had 8% of those who had heard of glaucoma from the radio but had not listened to the actual interview.

The above findings indicate that further research is required to determine the best method of reaching our target population through radio. Other media may need to be considered.

Strengths and limitations

There were two main strengths to this study. The first strength being that as far as we are aware, this is the first study to actually assess the impact of two different media sources aimed at raising awareness for glaucoma. Secondly, the two different populations highlighted patterns that were population-specific as were the strengths of responses.

The sampling method used is limited. Convenience sampling may not produce a representative population sample as it relies on people who can be accessed easily and conveniently. Although research was carried out before undertaking the study, our choice of media may not have been the best form for our message to reach our target population. Our study used only one radio interview and one newspaper advert which limits their exposure. A larger study would run a single advertisement/interview or a series, for a number of weeks.

For any health promotion package to be successful it needs to be reinforced by extensive public relations and promotions including media advocacy. This pilot study is part of the development of materials to be used in a full-scale health promotion package for glaucoma. It has provided us with a valuable insight for the use of media and its dissemination. The results show a positive



outcome to our original question and will play a crucial part in the development of a targeted health promotion campaign.

Acknowledgements

This study was generously funded by the Thomas Pocklington Trust. We are grateful to all who participated in this study. To Kamal Sharma who undertook the radio interview in Hindi on Sunrise Radio and produced the script for the Hindi Advertisements and Daksha Patel who carried out the Hindi focus groups. We would like to thank Melvyn Hillsdon and Patrick Branigan at the London School of Hygiene and Tropical Medicine for their excellent advice.

References

- 1 Gibson JM, Rosenthal AR, Lavery J. A study of the prevalence of eye disease in the elderly in an English community. *Trans Ophthalmol Soc UK* 1985; **104** (Part 2): 196–203.
- 2 Martinez GS, Campbell AJ, Reinken J, Allan BC. Prevalence of ocular disease in a population study of subjects 65 years old and older. *Am J Ophthalmol* 1982; **94**(2): 181–189.
- 3 Bengtsson B. The prevalence of glaucoma. *Br J Ophthalmol* 1981; **65**(1): 46–49.
- 4 Dandona L, Dandona R, Srinivas M, Mandal P, John RK, McCarty CA *et al*. Open-angle glaucoma in an urban population in southern India: the Andhra Pradesh eye disease study. *Ophthalmology* 2000; **107**(9): 1702–1709.
- 5 Sommer A, Tielsch JM, Katz J, Quigley HA, Gottsch JD, Javitt JC *et al*. Racial differences in the cause-specific prevalence of blindness in east Baltimore. *N Engl J Med* 1991; **325**(20): 1412–1417.
- 6 Tielsch JM, Sommer A, Katz J, Royall RM, Quigley HA, Javitt J. Racial variations in the prevalence of primary open-angle glaucoma. The Baltimore Eye Survey. *JAMA* 1991; **266**(3): 369–374.
- 7 Mitchell P, Smith W, Attebo K, Healey PR. Prevalence of open-angle glaucoma in Australia. The Blue Mountains Eye Study. *Ophthalmology* 1996; **103**(10): 1661–1669.
- 8 Coffey M, Reidy A, Wormald R, Xian WX, Wright L, Courtney P. Prevalence of glaucoma in the west of Ireland. *Br J Ophthalmol* 1993; **77**(1): 17–21.
- 9 Donovan R, Owen N. Social Marketing and population interventions. In: Dishman, RK (Ed). *Advances in Exercise Adherence*. Human Kinetics: Champaign, IL, 1994.
- 10 Tones K. Changing theory and practice: trends in methods, strategies and settings in health education. *Health Educ J* 1993; **52**: 126–139.
- 11 Fraser S, Bunce C, Wormald R, Brunner E. Deprivation and late presentation of glaucoma: case-control study. *BMJ* 2001; **322**(7287): 639–643.
- 12 Ealing Council. *Basic Skills Agency* 1997.
- 13 Patel D. Barriers to uptake of available ophthalmic services among the Asian community in Ealing. *LSHTM Personal Communication*.
- 14 Douglas J. Silent Cries: reflections on men's health promotion. In: Jones L, Sidell M and Douglas J (Eds). *The Challenge of Promoting Health*. Palgrave Macmillan, 2002, pp 226–237.
- 15 Weatherburn P, Henderson L, Reid D, Branigan P, Keogh P, Hickson F. Advertising Awareness: Evaluation of CHAPS national HIV Prevention Adverts and Leaflets Targeted at Gay Men 1996 to 2000. Stigma Research, 2001.

Poor public health knowledge about glaucoma: fact or fiction?

H Baker¹, SN Cousens² and IE Murdoch^{1,3}

CLINICAL STUDY

Abstract

Purpose To document public awareness and knowledge of glaucoma.

Patients and methods The study used health knowledge questionnaires. (a) A short, structured telephone interview was performed with a nationally representative sample of 1009 people. (b) A more detailed questionnaire was administered in two contrasting regions by telephone (500 interviews from the Isle of Wight and 226 interviews from Ealing) or face to face (300 interviews from Ealing).

Results Between 71 and 93% of those interviewed by telephone reported having heard of glaucoma, compared with only 23% of those interviewed face to face in Ealing. Of those who reported having heard of glaucoma, over 80% had at least some knowledge about the disease.

Conclusion This is the first study of public awareness of glaucoma across the UK. We found a relatively high level of awareness and knowledge of glaucoma in the general UK population, but identified at least one pocket of poor knowledge in a specific sub-population.

Eye (2009) 0, 000–000. doi:10.1038/eye.2009.155

Keywords: glaucoma; knowledge; public

Introduction

Estimates suggest that glaucoma affects some 67 million people worldwide,¹ and it is one of the major causes of preventable blindness in the UK.² Owing to its slow progression, individuals do not notice any problems in the early stages of the disease. In developed countries, only half of all glaucoma sufferers are diagnosed and receiving treatment at any given time.^{3,4}

In the UK, over 95% of referrals for suspected glaucoma are by high street optometrists among

individuals attending for refraction.⁵ Not infrequently, patients are blind or severely handicapped by the time of referral. Grant and Burke⁶ estimated that one-third of the patients who were blind from glaucoma had become so before they sought medical attention. This finding is consistent with other studies.^{7,8} Unfortunately, once damage has occurred to the optic nerve, it cannot be reversed; so early detection and treatment of the disease are important to preserve vision.^{6,9}

It has been suggested that the phenomenon of late diagnosis could be due, in part, to low public awareness of glaucoma. Several studies outside the UK^{10,11} have reported poor knowledge of glaucoma (having heard of glaucoma and knowledge about glaucoma).

To date, public awareness and knowledge of glaucoma in the UK have not been investigated. This study aimed to address this gap.

Materials and methods

The study comprised of two components. In the first component, detailed interviews were performed with 500 individuals in the Isle of Wight and 526 individuals in Ealing. The interviews in the Isle of Wight and 226 interviews in Ealing were done by telephone. Studies in other areas including breast and ovarian cancer¹² and sexual behaviour^{13,14} have used this method successfully. In some cases, it has been found that a telephone interview is more suitable because the remoteness between the interviewer and respondent can encourage greater honesty.^{15,16}

However, it was noted that the telephone interview procedure in Ealing yielded very few respondents from ethnic minorities despite the availability of Hindi-speaking interviewers. To access ethnic minorities in Ealing, 300 face-to-face interviews were performed in individuals' homes and places of worship in their normal spoken language (Hindi, Gujarati or Punjabi).

¹Institute of Ophthalmology, University College London, London, UK

²Department of Epidemiology and Population Health, Infectious Disease Epidemiology Unit, London School of Hygiene and Tropical Medicine, London, UK

³Moorfields Eye Hospital, London, UK

Correspondence: H Baker, Institute of Ophthalmology, University College London, Nov-43, Bath Street, London EC1V 9EL, UK
Tel: +44 020 7608 6896;
Fax: +44 020 7250 3207.
E-mail: h.baker@ucl.ac.uk

Received: 22 January 2009
Accepted in revised form: 28 May 2009

Funding source: This survey was kindly funded by the Guide Dogs for the Blind Association. The grant was unrestricted and investigators were given complete freedom in the design, analysis and interpretation of the data. This work has been presented at the 8th General Assembly of the International Agency for the Prevention of Blindness in August 2008.

For the telephone interviews, a sample of landline telephone numbers was supplied by Survey Sampling Incorporated using their Equal Probability of Selection Method (EPSEM). The EPSEM database has been created from OfTel data, using the basic 'building blocks' from which BT and all telephone providers generate telephone numbers. This means that all numbers have an equal probability of selection, and ex-directory and cable telephone numbers are included.

The face-to-face interviewees were identified by the interviewer attending all places of worship. These are located all around the borough and were a good place to reach our target population. Participants were also selected by knocking on peoples' doors in streets that had been selected before the interviews took place to ensure the whole area was covered.

All methods used quota sampling by age group and all participants reported being resident within the study area.

In the light of the findings from the Isle and Wight and Ealing, we then performed a national telephone survey of 1009 individuals in English using the same random telephone dialling methods.

In addition to the questions to determine social class grading (NSEC), two questions were asked:

1. Have you heard of glaucoma?
2. What do you think glaucoma is? Just tell me in your own words.

Questionnaire

The questionnaire was designed in conjunction with British Marketing Research Bureau (BMRB), specialists in the field, and in liaison with researchers with experience in the area of glaucoma health knowledge.^{10,17} Two agencies (BMRB and Ethnic Media Focus) carried out the interviews. Care was taken in the wording of questions to avoid leading questions and in their ordering to avoid questions, which could inform subsequent responses. The questionnaire was piloted and modified in the light of that experience. Interviews carried out in languages other than English used 'local' terms for glaucoma where appropriate. The same questionnaire with a standard introduction was used for all interviews excluding the national sample. The questionnaire started with general health questions that included eye-specific topics (eg medical checks in last 12 months, diseases heard of). Open questions on glaucoma and cataract were then followed by more detailed questions. Glaucoma knowledge was assessed by 14 true/false questions. The national sample was an omnibus survey carried out by the BMRB, which was standardised.

The open responses were 'scored', being awarded +1 for a correct point concerning the disease and -1 for an incorrect point concerning the disease. Individuals with a score below 1 were classified as having no knowledge, those with a score of 1 were classified as having minimal knowledge and those with a score >1 as having some knowledge. An example of a correct answer would be 'build up of pressure in the eye', 'can lead to blindness' or 'can be treated with eye drops'. Incorrect responses include 'something to do with your blood', 'to do with poor diet' or 'cannot be treated'.

This study had ethical approval from Moorfields Eye Hospital Ethical Committee, Isle of Wight, Portsmouth and South East Hampshire Health Authority Ethical committee and Ealing Ethical committee.

Results

A total of 2071 interviews were completed. For the telephone interviews, we had 2.5 refusals for every acceptance compared with 2.3 refusals for every face-to-face interview. The demographic and socio-economic characteristics of four samples are shown in Table 1. There were similar numbers of male and females. The national sample included individuals aged <35 years, but did not include anyone in the 'routine', 'semi-routine' or unemployed groups.

Of the 2071 individuals interviewed, 1531 (74%) reported having heard of glaucoma. The most striking observation with respect to these responses was the major difference in the proportion having heard of glaucoma between the Ealing face-to-face interviews (23%) and the other groups (78% or greater) (Table 1). Eleven regions were sampled in the national sample. The proportion who had heard of glaucoma between regions ranged from 71 to 86% ($\chi^2 = 25.8$ $P = 0.17$). In unadjusted analyses, females ($P = 0.001$) aged over 34 years ($P = 0.02$) and higher social class ($P < 0.001$) were all associated with an increased probability of having heard of glaucoma.

Validity

In the detailed interviews, those who reported having never heard of glaucoma or cataract were asked a second time if they were sure. Concordance of responses was 96% for glaucoma and 94% for cataract. The amount of knowledge professed in seven individuals who only answered positively for having heard of glaucoma on the second asking was very low suggesting good repeatability. The validity of responses is supported by the fact that none of the 120 who said they had only heard of the name glaucoma gave a response in the

Table 1 Distribution by sex, age, area and NSECa for having heard of glaucoma

	<i>IoW telephone</i>	<i>Ealing telephone</i>	<i>National survey</i>	<i>Ealing face-to-face</i>	<i>Total</i>
Sex					
Male	205/226 (91%)	83/115 (72%)	364/477 (76%)	40/165 (24%)	692/983 (70%)
Female	260/274 (95%)	123/147(84%)	427/532 (80%)	29/135 (21%)	839/1088 (77%)
Age (years)					
0-34	—	—	170/258 (66%)	—	170/258 (66%)
35-44	60/67 (90%)	48/57 (84%)	181/227 (80%)	6/48 (13%)	295/399 (74%)
45-54	112/114 (98%)	59/78 (76%)	137/158 (87%)	36/94 (38%)	344/444 (77%)
55-64	131/140 (94%)	33/44 (75%)	130/159 (82%)	17/75 (23%)	311/418 (74%)
65+	161/178 (90%)	61/78 (78%)	162/193 (84%)	10/83 (12%)	394/532 (74%)
NSECa					
Higher professional	46/47 (98%)	17/19 (89%)	174/199 (87%)	7/14 (50%)	244/279 (87%)
Lower professional	101/108 (94%)	29/35 (83%)	264/329 (80%)	7/19 (37%)	401/491 (82%)
Intermediate	58/61 (95%)	19/23 (83%)	148/191 (77%)	10/23 (43%)	235/298 (79%)
Small employers	21/22 (95%)	1/1 (100%)	79/114 (69%)	8/36 (22%)	109/173 (63%)
Technical	28/30 (93%)	13/14 (93%)	104/143 (73%)	9/24 (38%)	154/211 (73%)
Semi-routine	54/61 (89%)	30/40 (75%)	—	10/50 (20%)	94/151 (62%)
Routine	54/58 (93%)	10/18 (56%)	—	15/98 (15%)	79/174 (45%)
Unemployed	3/4 (75%)	5/12 (42%)	—	0/20 (0%)	8/36 (22%)

section, in which they were asked to describe it. A similar finding was true for cataract.

A logistic regression model was then constructed with 'heard of glaucoma' as the outcome (Table 2). The results are consistent with those of the crude analysis presented in Table 1.

Respondent's knowledge of glaucoma was assessed in two ways. First, those interviewed were asked how much they considered they knew about glaucoma. Second, an open-ended question was asked 'What do you think glaucoma is? Just tell me in your own words'. Not all those who reported having heard of glaucoma responded to this question (1362/1531 (89%)). Of those who responded, 86% gave an answer that included some reference to the eye. Table 3 shows the results of these two assessments.

Discussion

The first major finding of this study is that more people have heard of glaucoma than suggested by patient and professional perceptions.¹⁸⁻²⁰ However, we found much lower awareness in the face-to-face interviews in an ethnic minority population. One possible explanation for our findings is that the telephone sampling procedure resulted in bias towards a more aware population. Although the low response rate (about one-third) provides substantial scope for selection bias, it is not lower than that reported for other telephone surveys.²¹ In addition, our results agree with other studies in developed countries.^{10,11,17,22}

Table 2 Odds ratios for the associations between the outcome 'having heard of glaucoma' and sex, age, sampling source and NSECa

<i>Variable</i>	<i>Adjusted odds ratios (95% confidence interval)</i>	<i>P-value</i>
Sex		
Female	1.0	
Male	0.75 (0.58, 0.96)	0.02
Age (years)		
<35	1.0	
35-44	2.10 (1.41, 3.13)	
45-54	4.26 (2.71, 6.70)	<0.0001
55-64	2.43 (1.59, 3.72)	
65+	2.30 (1.52, 3.49)	
Source		
IoW telephone	1.0	
Ealing telephone	0.25 (0.14, 0.44)	
National telephone	0.23 (0.14, 0.38)	<0.0001
Ealing face-to-face	0.03 (0.02, 0.04)	
*NSECa		
Higher managerial	1.0	
Lower managerial	0.62 (0.37, 0.98)	
Intermediate	0.55 (0.34, 0.90)	
Small employers	0.33 (0.20, 0.56)	
Lower supervisory	0.40 (0.24, 0.67)	<0.0001
Semi-routine	0.24 (0.13, 0.46)	
Routine	0.18 (0.10, 0.34)	
Unemployed	0.05 (0.02, 0.14)	

It could be that the difference in awareness of glaucoma between the face-to-face interviewees and the telephone interviewees does not simply show selection

Table 3 Level of knowledge about glaucoma

Knowledge	IoW telephone	Ealing telephone	Ealing face to -face	Whole country ^a	Total
<i>Own assessment</i>					
Nil	96 (20%)	3 (1%)	21 (31%)	—	120 (15%)
Small	145 (30%)	65 (29%)	16 (24%)	—	236 (30%)
Some	241 (50%)	158 (70%)	30 (45%)	—	429 (55%)
<i>Open question responses</i>					
Nil	96 (25%)	50 (32%)	2 (4%)	107 (14%)	255 (18%)
Small	160 (42%)	64 (41%)	11 (24%)	460 (58%)	695 (50%)
Some	129 (34%)	44 (28%)	33 (72%)	224 (28%)	430 (31%)

^aThe nationally representative sample was not asked this self-assessment question.
NB: Fewer answered the open-ended question.

bias in the two different recruitment methods, but could reflect an underlying difference. This is supported by the fact that other studies in developed countries using face-to-face interviews had similar results to those found in our telephone sample.

In addition to a large proportion having heard of glaucoma, over 80% of those who had heard of the disease reported some knowledge about it. This profession of knowledge was supported by the proportion of people who showed correct knowledge in response to the open-ended question.

The low level of awareness in the face-to-face interviews in Ealing is important in highlighting a potential deficiency of random telephone interviews. In Ealing, the telephone sampling method found the same level of awareness of glaucoma as the national sample (78%). The face-to-face interviews found 23% awareness. It can be hypothesized that the telephone is more likely to be answered by an English-speaking member of the family who is more informed, or not answered at all. This result is important for the interpretation of other studies, in which sampling was undertaken by random digit dialling. Ethnic or other minorities may not be properly represented. This phenomenon has not been reported earlier.^{23,24}

In Ealing, it was in the Indian population in which we observed a low awareness of glaucoma. Although face-to-face interviewers used colloquial terms for the word glaucoma for clarity when required, it is possible that this reflects the issues of translation rather than poor understanding of glaucoma. However, we think that this is unlikely, as in the same questionnaire participants were asked if they had heard of cataract, to which 99% of the population answered yes and diabetic retinopathy, of which 72% had heard.

The areas of low awareness are a concern, and in the case of the ethnic minorities in Ealing, we are addressing this with public health campaign to see if awareness about glaucoma can be improved. Interestingly, those

that were aware of glaucoma in this subgroup had a high degree of knowledge of glaucoma.

The higher level of awareness contrasts with the findings from other countries,^{10,22} and from the earlier qualitative studies.^{18,20} This observation argues against a lack of awareness being the main reason why only 50% of glaucoma cases have been diagnosed at any one time.

Awareness of glaucoma was slightly higher among females than males (77 vs 71%). This finding is consistent with other studies.^{10,25} Awareness was lower among those aged <35 years. The work of Michielutte *et al*²⁵ also found younger people to be less knowledgeable.

People from higher social class were more aware, although there is a bias in the national sample; no individuals from semi-routine, routine or unemployed were sampled. This is likely to mean that we have a slight over estimate of numbers who have heard of glaucoma in the national sample. However, the results from the other telephone interviews include these grades and show similar proportions having heard of glaucoma. The Whitehall study²⁶ found that lower social classes had a higher incidence of disease and discussed aspects, such as lifestyle, environmental and occupational exposures, including the psychosocial to consider as factors contributing to this. If we assume that awareness leads to an increased chance of diagnosis, then it is more likely for the lower social classes to be undiagnosed in the community going blind from the disease. This is consistent with Fraser *et al*,²⁷ who have shown that people in lower social classes are more at risk of going blind from glaucoma because of late presentation.

Conclusions

It appears that it would be wrong to assume that people in the UK have not heard of glaucoma. Among those responding to our study, not only had the majority of older people heard of the disease, but they also had a degree of knowledge about the disease. Why then are

only 50% of glaucoma suffers diagnosed and receiving therapy? The RNIB have reported one of the barriers to eyes tests in older people to be lack of awareness.²⁸ In the light of our findings, this requires further investigation.

This is the first study of public health knowledge of glaucoma across the UK. This study observed a higher than anticipated level of awareness and knowledge of glaucoma and highlighted a limitation of a telephone survey approach. In our case, a telephone survey missed a pocket of low awareness.

Acknowledgements

This survey was generously funded by the Guide Dogs for the Blind. We are grateful to BMRB for helping us to design the questionnaire and to Ethnic Media Focus and BMRB for data collection. We would also like to thank all who participated in this study.

References

- Quigley HA. Number of people with glaucoma worldwide. *Br J Ophthalmol* 1996; **80**(5): 389–393.
- Evans JR, Fletcher AE, Wormald RP. Causes of visual impairment in people aged 75 years and older in Britain: an add-on study to the MRC Trial of Assessment and Management of Older People in the Community. *Br J Ophthalmol* 2004; **88**(3): 365–370.
- Sommer A, Tielsch JM, Katz J, Quigley HA, Gottsch JD, Javitt JC et al. Racial differences in the cause-specific prevalence of blindness in east Baltimore. *N Engl J Med* 1991; **325**(20): 1412–1417.
- Tielsch JM, Sommer A, Katz J, Royall RM, Quigley HA, Javitt J. Racial variations in the prevalence of primary open-angle glaucoma. The Baltimore Eye Survey. *JAMA* 1991; **266**(3): 369–374.
- Bell RW, O'Brien C. Accuracy of referral to a glaucoma clinic. *Ophthalmic Physiol Opt* 1997; **17**(1): 7–11.
- Grant WM, Burke Jr JF. Why do some people go blind from glaucoma? *Ophthalmology* 1982; **89**(9): 991–998.
- Sheldrick JH, Ng C, Austin DJ, Rosenthal AR. An analysis of referral routes and diagnostic accuracy in cases of suspected glaucoma. *Ophthalmic Epidemiol* 1994; **1**(1): 31–39.
- Coffey M, Reidy A, Wormald R, Xian WX, Wright L, Courtney P. Prevalence of glaucoma in the west of Ireland. *Br J Ophthalmol* 1993; **77**(1): 17–21.
- Vogel R, Crick RP, Newson RB, Shipley M, Blackmore H, Bulpitt CJ. Association between intraocular pressure and loss of visual field in chronic simple glaucoma. *Br J Ophthalmol* 1990; **74**(1): 3–6.
- Livingston PM, Lee SE, De Paola C, Carson CA, Guest CS, Taylor HR et al. Knowledge of glaucoma, and its relationship to self-care practices, in a population sample. *Aust NZ J Ophthalmol* 1995; **23**(1): 37–41.
- Pfeiffer N, Kriegelstein GK, Wellek S. Knowledge about glaucoma in the unselected population: a German survey. *J Glaucoma* 2002; **11**(5): 458–463.
- Hallowell N, Murton F, Statham H, Green JM, Richards MP. Women's need for information before attending genetic counselling for familial breast or ovarian cancer: a questionnaire, interview, and observational study. *BMJ* 1997; **314**(7076): 281–283.
- Beckman LJ, Harvey SM, Thorburn S, Maher JE, Burns KL. Women's acceptance of the diaphragm: the role of relationship factors. *J Sex Res* 2006; **43**(4): 297–306.
- Patrick ME, Maggs JL, Abar CC. Reasons to have sex, personal goals, and sexual behavior during the transition to college. *J Sex Res* 2007; **44**(3): 240–249.
- Sturges J, Hanrahan K. Comparing telephone and face-to-face qualitative interviewing a research note. *Qualitative Res* 2004; **4**(1): 107–118.
- Fenig S, Levav I, Kohn R, Yelin N. Telephone vs face-to-face interviewing in a community psychiatric survey. *Am J Public Health* 1993; **83**(6): 896–898.
- Attebo K, Mitchell P, Cumming R, Smith W. Knowledge and beliefs about common eye diseases. *Aust NZ J Ophthalmol* 1997; **25**(4): 283–287.
- Burns J, Barrett G, Murdoch I. The experiences of patients with suspect glaucoma. *Ophthalmic Nurs* 2001; **5**(3): 8–11.
- Patel D, Baker H, Murdoch I. Barriers to uptake of available ophthalmic services among the Asian community in Ealing. *Health Educ J* 2006; **65**(3): 267–276.
- Green J, Siddall H, Murdoch I. Learning to live with glaucoma: a qualitative study of diagnosis and the impact of sight loss. *Soc Sci Med* 2002; **55**(2): 257–267.
- Nicolaas G, Lynn P. Random-digit dialling in the UK: viability revisited. *J R Stat Soc [Ser A]* 2002; **165**(Part 2): 297–316.
- Lau JT, Lee V, Fan D, Lau M, Michon J. Knowledge about cataract, glaucoma, and age related macular degeneration in the Hong Kong Chinese population. *Br J Ophthalmol* 2002; **86**(10): 1080–1084.
- Newman W. Survey research. In: *Social Research Methods: Qualitative and Quantitative Approaches*. Allyn and Bacon, 2003, pp 289–290.
- Nicolaas G. *Sampling Issues for Telephone Surveys in Scotland* 2004 [cited; www.bioss.ac.uk/staff/admin/rsse/2003-2004/presentations/germy_nicolaas.ppt.].
- Michielutte R, Diseker RA, Stafford CL, Carr P. Knowledge of diabetes and glaucoma in a rural North Carolina community. *J Community Health* 1984; **9**(4): 269–284.
- Marmot MG, McDowall ME. Mortality decline and widening social inequalities. *Lancet* 1986; **2**(8501): 274–276.
- Fraser S, Bunce C, Wormald R, Brunner E. Deprivation and late presentation of glaucoma: case-control study. *BMJ* 2001; **322**(7287): 639–643.
- RNIB. Older People and Eye Tests: Don't Let Age Rob You of Your Sight 2007 [cited 13/02/2008]; available from: www.rnib.org.uk/xpedio/groups/public/documents/publicwebsite/public_olderereyereport.pdf.

Q1

Can a public health intervention improve awareness and health-seeking behaviour for glaucoma?

H Baker,¹ I E Murdoch^{1,2}

¹ Department of Epidemiology and International Eye Health, Institute of Ophthalmology, London, UK; ² Moorfields Eye Hospital, City Road, London, UK

Correspondence to: Mrs H Baker, Department of Epidemiology and International Eye Health, Institute of Ophthalmology, 11–43 Bath Street, London EC1V 9EL, UK; h.baker@ucl.ac.uk

Accepted 20 September 2008
Published Online First
6 October 2008

ABSTRACT

Aim: To investigate whether a public education campaign can increase awareness and change help-seeking behaviour with respect to ocular health in an Indian population.

Methods: A health knowledge questionnaire was used investigating and assessing the health campaign. The health campaign comprised four components: (1) television, (2) local press, (3) local radio and (4) places of worship. The target population were Indian residents in Southall, Ealing aged 60+. The aim was to get people to go and have their eyes tested at their local optometric practice. Optometric practices within the borough of Ealing collected sight-test data for the study over 6 months before and after the advertising campaign.

Results: The repeat in-depth glaucoma knowledge questionnaire showed a significant increase in the number of people who had heard of glaucoma rising from 22% to 53%. Before intervention, most people had heard about glaucoma from their GP, friend or relative. After intervention, the majority (69%) had heard of glaucoma from the radio.

Conclusion: This study has shown a significant increase in awareness from using different kinds of media and has shown radio to be the most effective in our target community. Although the campaign has raised awareness, this study has not shown a change in health-seeking behaviour.

Primary open angle glaucoma affects 1–2% of people over 40 years of age in Caucasian and Indian populations.^{1–4} The disease is strongly age-related, resulting in a progressive, irreversible loss of the field of vision. Largely asymptomatic until the late stages, it is the major cause of preventable blindness in older people in the UK. In the developed world, only 50% of those with the disease are diagnosed and receiving therapy.^{5–8}

From a pilot qualitative study⁹ into the impact of glaucomatous visual-field loss on patients' lifestyles, we showed that, although there were common referral triggers, patients' symptoms were not specific. Poor public and patient knowledge of glaucoma may adversely influence individuals having regular sight tests. Individuals' risk of vision loss could be reduced if we successfully encouraged those at risk of blinding eye disease to obtain a comprehensive ophthalmic examination on a regular basis. Patients also reported that greater public awareness might increase public understanding of their disability and its impact on their lives.¹⁰

Research and evaluation of the use of mass media in health promotion have led to an acceptance that mass media can be used effectively

within certain areas.¹¹ It is accepted that it can raise consciousness about some health issues, convey simple information and change behaviour. This study is the first to investigate whether a public education campaign can increase awareness and change help-seeking behaviour with respect to ocular health in an Indian population.

METHODS

Study location

Southall, Ealing was the chosen area for our study. A pilot study has shown that knowledge of glaucoma in the Indian population in Southall Ealing was low.¹² Our research group has gained considerable background information on positive predictive values of glaucoma referrals and optometric practice within the area.¹³ As a result, we have excellent working relationships with the optometric community.

In 2001, the Borough of Ealing had a population of 300 948, of which 46 865 were over 60, and 49 734 were of Indian origin.

Baseline and outcome measures

A health-knowledge questionnaire was carried out, 300 interviews pre- and 307 interviews postintervention. Following verbal consent, the questionnaire started with general health questions that included eye-specific topics (medical checks in last 12 months, diseases heard of). Open questions on glaucoma and cataract were then followed by more detailed questions. Glaucoma knowledge was assessed by 14 true/false questions (see appendix A).

Face-to-face interviews were performed in individuals' homes and places of worship in their normal spoken language (Hindi, Gujarati or Punjabi), as we have found this a more appropriate method of data collection in the Indian population allowing for greater parity.

All optometric practices within the borough of Ealing were asked to collect data for the study. Practices collected data for 6 months before and after the advertising campaign.

Four practices collected data for 1 month pre-/postcampaign, asking people what had motivated them to come for an eye tests.

Advertising campaign

The health intervention comprised four components and ran throughout the month of September 2006:

1. Adverts on the television: three adverts were translated into Hindi and were run daily on five different Asian television stations.

Clinical science

2. Adverts in the local press: English and Hindi adverts were run on alternate weeks in the local press. The Hindi advert was run in Asian Voice and Gujarat Samachar.
 3. Adverts and interviews on local radio: one radio commercial was produced and translated in to Hindi and Punjabi; it was broadcast daily on three different radio stations. There was also an interview with a glaucoma specialist on two of the radio stations.
 4. Posters placed in places of worship: a poster was designed to be placed on the walls in places of worship in Southall.
- Our target population were Indian people aged 60 and above who were residents in Southall. The aim of the campaign was to get people to go and have their eyes tested at their local optometric practice.

Analysis

All data from the Optometric practices and the health knowledge questionnaire pre- and postintervention were coded and cleaned. Tests of significance were carried out to assess statistical significance for differences in proportion and logistic regression undertaken to assess confounding. All statistical analyses were carried out using Stata7 (pub StataCorp 2001).

Ethical approval

This study had ethical approval from Moorfields Eye Hospital Ethical Committee, Isle of Wight, Portsmouth & South East Hampshire Health Authority Ethical Committee and Ealing Ethical Committee.

RESULTS

Health-knowledge questionnaire: awareness of glaucoma

A total of 607 results were used in the analysis. The demographic characteristics are shown in table 1. It can be seen that the two samples were broadly similar, apart from a higher proportion of Hindus prior to the intervention and higher proportion of Sikhs after the intervention.

Table 1 Demographic composition of samples interviewed for the health-knowledge pre- and postadvertising campaign

	Preadvertising N = 300	Postadvertising N = 306
Age group		
40–44	48 (16%)	49 (16%)
45–49	43 (14%)	43 (14%)
50–54	50 (17%)	66 (22%)
55–59	33 (11%)	40 (13%)
60–64	43 (14%)	29 (9%)
65–69	40 (13%)	34 (11%)
70–74	25 (8%)	28 (9%)
75–79	7 (2%)	13 (4%)
80+	11 (4%)	5 (2%)
Gender		
Male	165 (55%)	180 (59%)
Female	135 (45%)	127 (41%)
Religion		
Hindu	109 (36%)	49 (16%)
Muslim	47 (16%)	55 (18%)
Seikh	142 (47%)	201 (66%)
Other	2	1

Validity

Both glaucoma and cataract respondents who answered that they had never heard of the disease were asked a second time if they were sure. The concordance of responses was 96% for glaucoma and 94% for cataract. The amount of knowledge professed in seven individuals who only answered positively for having heard of glaucoma on the second asking was very low, suggesting validity. Further validity was suggested by the fact that none of the 120 who said they had only heard of the name glaucoma gave a response in the section where they were asked to describe it. This validity was also true for cataract.

The proportion who had heard of glaucoma increased from 67 (22%) to 163 (53%) ($p < 0.000$). In contrast, the proportion who had heard of other diseases in interviews after the intervention was lower, emphasising the unique impact on glaucoma (table 2).

Table 3 shows where individuals had heard of glaucoma. Prior to the intervention, those who had heard of glaucoma reported having learnt from their GP (19%) or a friend or relative (36%) an awareness gained by word of mouth; none had heard via the radio. After the campaign, 111 (69%) of those who had heard of glaucoma reported having done so via the radio.

As the impact was by far the most profound in those listening to radio, the numbers listening to radio stations who had heard of glaucoma pre- and postintervention were investigated (table 4). It can be seen that the effect seems to be spread across all three major Asian stations with a similar increase in the proportion who had heard for glaucoma from just over 20% to around 60%.

The questionnaire included detailed questions for social class grading by NS-SEC. These grades were contracted to NS-SECA. There was no major difference between the social class structure of the cohorts interviewed pre- and postintervention, and the increase in knowledge of glaucoma was seen in each social class category. There was a strong trend for awareness of glaucoma being more common in the higher social classes.

In a similar fashion, there was a grade of awareness with educational achievement. The effect of the intervention was seen in all groups but was clearly most marked in those with lower levels of education. Individuals with CSE ungraded/NVQ and lower saw an increase from 8% pre- to 44% post- who had heard of glaucoma.

HEALTH-KNOWLEDGE QUESTIONNAIRE: KNOWLEDGE OF GLAUCOMA

Of those that had heard of glaucoma, about half (109 (48%)) professed any more knowledge than having simply heard of the condition. There were proportionately more professing knowledge prior to the campaign (46/67 (69%)) than in those after the campaign (63/163 (39%)).

After an open-ended question asking what they thought glaucoma was, 14 true/false questions were asked about glaucoma. See appendix A. No clear pattern was shown between groups pre- and postintervention in terms of knowledge. The absolute numbers answering correctly was the same between the two groups (41 pre- and 41 post-).

More individuals reported having had an eye test in the last year after the campaign. There is a suggestion that the knowledge of glaucoma in part accounted for this effect, since the increased number who had heard of glaucoma also seem to have attended for a recent eye test. These results are shown in table 5. A χ^2 test was used preintervention and again postintervention. It was only significant postintervention

Table 2 Number who had heard of eye diseases pre- and postintervention

Disease	Preintervention heard (%)	Postintervention heard (%)	χ^2
Cataract	298 (99)	236 (77)	$p < 0.000$
Macular degeneration	21 (7)	0 (0)	$p < 0.000$
Glaucoma	67 (22)	163 (53)	$p < 0.000$

where a higher proportion of those who had heard of glaucoma had had a recent eye test.

Logistic regression was undertaken for the outcome having heard of glaucoma (table 6). The crude odds showed significant explanatory variables to be prepostintervention, having an eye test in the last year, having other health checks in the last year (dental, BP, cholesterol) and having heard of other ocular conditions (cataract, diabetic eye disease, macular degeneration). There was no association between having heard of glaucoma and having heard of most other systemic diseases. Younger people were more likely to have heard of glaucoma. Similarly, being in a higher social class meant one was more likely to have heard of glaucoma as did having a higher educational qualification. The data were examined for collinearity between the level of educational qualification and social class, but this was not found. A more complex model was constructed to look for confounding including the variables age, sex, having an eye test in the last year, educational qualification, social class and having heard of cataract. It can be seen that the effect of the intervention and knowledge of another eye disease was increased with correction of confounding. The other effects were not substantially changed.

OPTOMETRIC DATA

There were 26 practices in the area at the start of the project. Twenty practices participated in data collection in 2004 contributing a range of 1–26 weeks of data with an average of 14.5 weeks. Twelve practices participated in data collection in 2007 contributing a range of 1–24 weeks of data with an average of 13.5 weeks. Four practices had closed in the intervening period (one for refitting and one that did not respond in 2004). No new practices had opened in the area.

Wait times are not recorded in the results, as practices had no wait times. There was no major change in the average number of appointments per practice per week between 2004 and 2007

(32 vs 31). This was true if restricted to those aged 40 years and over (19 vs 20) and those aged 60 years and over (12 vs 11).

For the 11 practices with paired data from 2004 and 2007, there were changes in both directions of increased and decreased appointments. This was predominantly related to changes in staff or opening times.

Optometrists at four practices asked people attending for eye tests what had motivated them to attend. The main reasons were a routine appointment implying they had been sent a reminder letter from the practice, visual changes or discomfort, a recommendation from a GP/friend or they had glaucoma. Reasons for attending included visual symptoms, disease, recommendation and other health issues, but the most common reason was for a routine review. Out of a total of 1678, 655 (39%) gave this reason for attendance before the intervention, and this increased to 767/1507 (51%) after the intervention ($p = 0.001$).

DISCUSSION

Principal findings

The main finding of this study is that our health campaign more than doubled the proportion who had heard of glaucoma (22% to 53%). Although we used bright, colourful and frequently aired television adverts, it was the radio advert that had the most impact: 69% of those who had heard of glaucoma, had done so via the radio. Similarly, posters in community settings and adverts in papers had a much smaller effect.

The increased awareness of glaucoma was most marked following the campaign in those who also reported a recent health check for any disease. This suggests that a more health-conscious group who has tests and checks is more responsive to health campaigns. Age and sex made no difference.

The link between having heard of other eye conditions and having heard of glaucoma is less surprising, merely suggesting a more health-aware subpopulation. Interestingly, it was the younger age bands that were more likely to have heard of the disease.

Although the proportion who had heard of glaucoma rose strikingly following the campaign, the degree of knowledge about glaucoma did not really improve. This is not too surprising, since the campaign was only designed to improve awareness of the condition. It does, however, suggest that improved awareness does not lead to spontaneous self-education. The results concerning attendance for an eye examination are conflicting. A higher proportion reported having attended for an eye examination in the last year after the intervention, and most of these were people who had heard of glaucoma. However, the absolute numbers attending for eye examinations showed a slight decrease.

Relationship to other studies

In the UK, the Department of Health runs a number of large campaigns to improve public health.¹⁴ Sexual health, substance and alcohol abuse, obesity and smoking are some of the areas targeted. These campaigns work with legislation and the government to raise awareness and motivate change within

Table 3 Where they had heard of glaucoma in those that had reported having heard of glaucoma

Heard of glaucoma from	Pre (%)	Post (%)
Doctor/GP	13 (19%)	10 (6%)
Optometrist/optician	6 (9%)	1 (<1%)
Health professional	0 (0%)	1 (<1%)
Friend or relative	24 (36%)	14 (9%)
Friend or relative have disease	12 (18%)	2 (1%)
Leaflet or poster	1 (1%)	0 (0%)
TV	2 (3%)	8 (5%)
Radio	0 (0%)	111 (69%)
Newspaper/magazine	3 (4%)	4 (2%)
Patient	0 (0%)	2 (1%)
Just know	6 (9%)	3 (2%)
GP and radio	0 (0%)	3 (2%)
GP and newspaper/magazine	0 (0%)	1 (<1%)
TV and radio	0 (0%)	2 (1%)
Total	67	162

Clinical science

Table 4 Numbers who listened to the three major Asian radio stations who had heard of glaucoma

Radio	Preintervention		Postintervention	
	No (%) listening (%)	No of listeners (%) who had heard of glaucoma (%)	No (%) listening (%)	No of listeners (%) who had heard of glaucoma (%)
Sunrise	179 (60)	46 (26)	48 (16)	28 (58)
Punjab	68 (23)	14 (21)	58 (19)	34 (59)
Desi	138 (46)	27 (20)	146 (48)	98 (67)

Table 5 Proportion who had heard of glaucoma and reported recent eye test pre- and postintervention

	Preintervention $p = 0.4$		Postintervention $p < 0.001$	
	Not heard	Heard	Not heard	Heard
No recent eye test	86 (37%)	21 (31%)	45 (31%)	21 (13%)
Recent eye test	147 (63%)	46 (69%)	99 (69%)	142 (87%)
Total	233	67	144	163

the nation. Even with this backing, it has proven hard to influence change. It is impossible for the Department of Health to cover every health issue, and in many areas it falls to charities and health professionals to try and raise awareness and motivate behavioural change in their specialised area. Many such campaigns remain unassessed, unpublished or published internally. Areas where campaigns have been published include physical activity,¹⁵ diabetes^{16,17} and sexual health.¹⁸ Our campaign is similar to the diabetic and physical activity campaigns in that it was able to raise awareness but failed to have any significant influence on changing behaviour. Our study's strengths lay in its tight target population.

Strengths and limitations

This is the first study to assess the impact of an eye campaign in detail. The main limitation of this assessment is the cultural and area-specific nature of the campaign. The results are therefore only generalisable to other similar communities, and further research would need to be undertaken to assess impact in different communities. The data of optometrist visits for sight tests proved extremely difficult to collect in Ealing. The collection of data from community optometrists was extremely

patchy. This was a major limitation to the interpretation of any effect in terms of health-seeking behaviour as a result of the public health campaign. Our contrasting results suggested in the questionnaire highlights this limitation.

Implications for health professionals and policy makers

Lessons were learnt in the undertaking of this campaign. Inside community knowledge proved invaluable in gaining the trust and support of local community groups. Messages can be easily misinterpreted, and sensitivities need to be acknowledged. In some temples, the poster was refused; this reluctance to cooperate was overcome in other places of worship by taking along a colleague of the same religion. Attempts to gain funding from local business proved unsuccessful. This could be due to health being a low priority in this group.¹⁹ Funding was eventually raised through larger international bodies.

Cost is a major issue in any advertising campaign, and our finding shows that it is not always the most expensive method that can be the most effective. The radio is an important form of communication for our target group; it is made by their community for their community, and our research has shown it is a good way to reach this population. This finding emphasises

Table 6 Crude odds of numerous variables for the outcome of having heard of glaucoma

Explanatory variable for knowledge of glaucoma	Crude OR	Adjusted OR*
Prepostintervention	3.94 (2.77 to 5.60)†	6.41 (4.11 to 10.0)†
Increasing age (5-year bands)	0.91 (0.85 to 0.99)†	0.89 (0.80 to 0.99)†
Sex	0.99 (0.71 to 1.38)	1.35 (0.87 to 2.09)
Having an eye test in the last year	2.38 (1.60 to 3.54)†	1.99 (1.21 to 3.26)†
Educational qualification	0.70 (0.60 to 0.81)†	0.68 (0.56 to 0.83)†
Social class (NS-SECA)	0.79 (0.72 to 0.87)†	0.85 (0.76 to 0.95)†
Having a cholesterol check in the last year	2.65 (1.85 to 3.80)†	
Having a BP check in the last year	1.79 (1.12 to 2.86)†	
Having a dental check in the last year	2.00 (1.41 to 2.83)†	
Religion	0.93 (0.77 to 1.12)	
Having heard of cataract	5.78 (2.72 to 12.3)†	12.9 (5.36 to 30.9)†
Having heard of arthritis	1.03 (0.68 to 1.56)	
Having heard of diabetic eye disease	1.71 (1.23 to 2.38)†	
Having heard of psoriasis	1.55 (0.99 to 2.41)	
Having heard of Alzheimer's	1.07 (0.73 to 1.56)	
Having heard of macular degeneration	16.9 (3.39 to 73.2)†	
Having heard of tinnitus	0.95 (0.61 to 1.47)	
Having heard of multiple sclerosis	3.03 (1.83 to 5.02)†	

*Adjusted for prepostintervention, age, sex and having an eye test in last year.

†Significant at $p < 0.05$.

the importance of learning about one's target population. A radio advert is relatively cheap to produce and air, but we have shown that in the right community it can have a large effect. The radio reached 69% of the people who had heard of glaucoma postintervention.

CONCLUSION

This study has shown a major impact on disease, through radio, in particular in our target population. Before charities put money into media production, it is important that they look at who they want to reach and how they are going to achieve this.

Acknowledgements: We gratefully acknowledge individuals and organisations for their support and participation in the Ealing project, in particular: The Guide Dogs for the Blind Association, McCann Erickson, BMRB, Ethnic Media Focus and Cowboy Films. We would like to give special thanks to R Hutchinson who was instrumental at the start of this project.

Funding: This survey was kindly funded by the Guide Dogs for the Blind Association. The grant was unrestricted, and investigators were given complete freedom in the design, analysis and interpretation of the data.

Competing interests: None.

Ethics approval: Ethics approval was provided by Moorfields Eye Hospital Ethical Committee, Isle of Wight, Portsmouth & South East Hampshire Health Authority Ethical committee and Ealing Ethical committee.

Patient consent: Obtained.

REFERENCES

- Gibson JM, Rosenthal AR, Lavery J. A study of the prevalence of eye disease in the elderly in an English community. *Trans Ophthalmol Soc UK* 1985;**104**:196–203.
- Martinez GS, et al. Prevalence of ocular disease in a population study of subjects 65 years old and older. *Am J Ophthalmol* 1982;**94**:181–9.
- Bengtsson B. The prevalence of glaucoma. *Br J Ophthalmol* 1981;**65**:46–9.
- Dandona L, et al. Open-angle glaucoma in an urban population in southern India: the Andhra Pradesh eye disease study. *Ophthalmology* 2000;**107**:1702–9.
- Sommer A, et al. Racial differences in the cause-specific prevalence of blindness in east Baltimore. *N Engl J Med* 1991;**325**:1412–17.
- Tielsch JM, et al. Racial variations in the prevalence of primary open-angle glaucoma. The Baltimore Eye Survey. *JAMA* 1991;**266**:369–74.
- Mitchell P, et al. Prevalence of open-angle glaucoma in Australia. The Blue Mountains Eye Study. *Ophthalmology* 1996;**103**:1661–9.
- Coffey M, et al. Prevalence of glaucoma in the west of Ireland. *Br J Ophthalmol* 1993;**77**:17–21.
- Green J, Siddall H, Murdoch I. Learning to live with glaucoma: a qualitative study of diagnosis and the impact of sight loss. *Soc Sci Med* 2002;**55**:257–67.
- Ainlay S. *Day brought back my night: Ageing and vision loss*. London: Routledge, 1989.
- Tones K. Changing theory and practice: trends in methods, strategies and settings in health education. *Health Educ J* 1993;**52**:126–39.
- Baker H, Murdoch IE. Can a public health package on glaucoma reach its target population? *Eye* 2004;**18**:478–82.
- Theodossiadis J, Murdoch I, Cousens S. Glaucoma case finding: a cluster-randomised intervention trial. *Eye* 2004;**18**:483–90.
- Department of Health. Health improvement. <http://www.dh.gov.uk/en/PublicHealth/Healthimprovement/index.htm> (accessed 5 Oct 2008).
- Hillsdon M, et al. National level promotion of physical activity: results from England's ACTIVE for LIFE campaign. *J Epidemiol Community Health* 2001;**55**:755–61.
- Jackson DMA, et al. Public awareness of the symptoms of diabetes mellitus. *Diab Med* 1991;**8**:971–2.
- Singh BM, et al. Effect of advertising on awareness of symptoms of diabetes among the general public: the British Diabetic Association Study. *BMJ* 1994;**308**:632–6.
- Oakley A, et al. Sexual health education interventions for young people: a methodological review. *BMJ* 1995;**310**:158–62.
- Patel D, Baker H, Murdoch I. Barriers to uptake of available ophthalmic services among the Asian community in Ealing. *Health Education Journal* 2006;**65**:267–76.

APPENDIX

Glaucoma-knowledge questionnaire

The next set of statements are about Glaucoma. For each one, please can you tell me whether you think it is true or false

- ▶ Glaucoma causes a loss of peripheral vision.
- ▶ Glaucoma is caused by an infection of the eye.
- ▶ There is more than one type of glaucoma.
- ▶ Men are more likely to suffer from glaucoma than women.
- ▶ People of African descent are more likely to suffer from glaucoma.
- ▶ Glaucoma can be inherited.
- ▶ Glaucoma can cause permanent blindness.
- ▶ Glaucoma may be caused by increased pressure in the eye.
- ▶ The optic nerves at the back of the eye are affected by glaucoma.
- ▶ Glaucoma causes a skin to grow over the inside of the eye.
- ▶ Generally people do not develop glaucoma until they are over 40.
- ▶ Headaches are commonly associated with glaucoma.
- ▶ High blood pressure can lead to glaucoma.
- ▶ You usually know if you have glaucoma.